



UNIVERSITY OF
LIVERPOOL

**Caring for a family member with a life-limiting
illness:**

**Examining the interactions between patients,
family carers and health care professionals
across the illness trajectory.**

**Thesis submitted in accordance with the requirements of the
University of Liverpool for the degree of Doctor in Philosophy by**

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Declaration

I, Laurie Dunn, declare that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and that the material has not been submitted, either in whole or in part, for a degree at this or any other university.

Abstract

Introduction: This phenomenological study explores the interactions between patients, carers, and health and social care professionals from the perspective of bereaved family carers. The research presents models of care which attend to the current picture of care. These models are presented alongside experiential data from family caregivers.

Methods: Fifty-one retrospective narrative interviews were conducted with bereaved family caregivers of people with a life-limiting illness. Interviews were predominantly conducted face to face, in the North West of England. Interviews were transcribed verbatim and analysed from using thematic structural analysis. NVivo version 9 was used to manage the data.

Findings: The roles and interactions between patients, family carers and health and social work professionals differed significantly across place of care and across the illness trajectory. The findings examine the following areas of family caregivers' experiences: roles and relationships; uncertainty and reassurance; communication; and kindness and compassion in care.

Conclusions: Existing models of dyadic and triadic care fail to adequately address the complex dynamics of family caregiving. The models presented in this study demonstrate the direction of support and level of responsibility of care in home, hospice and hospital care environments. A partnership approach, where family caregivers feel supported and reassured by health and social care professionals is essential to improving carers' confidence in their role and satisfaction with the support they receive.

Key words: qualitative, life-limiting illness, end of life care, caregivers, interactions, triadic care.

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Contents

Chapter 1	Introduction	1
1.1	Study background	1
1.2	Definitions used in thesis	1
1.2.1	Defining ‘formal’ and ‘informal’ caregivers	1
1.2.2	Stages of the illness trajectory	2
1.2.3	Life-limiting illness	4
1.2.4	Palliative care	4
1.3	Supporting family caregivers: current policies and practice	5
1.3.1	National strategy	5
1.3.2	Regional strategy	10
1.4	My personal interest in this area	13
1.5	Developing the research question	13
1.6	Introduction to chapters	13
Chapter 2	Literature Review	15
2.1	Introduction	15
2.2	The search strategy	15
2.3	The needs of carers of people with life-limiting illnesses	23
2.4	Interventions to support family carers	25
2.5	The ‘burden’ of care	27
2.6	Positive aspects of caring	28
2.7	Interactions between systems of formal and informal care: partnerships in family care?	29
2.8	Priority areas for future research in supportive and palliative care	34
Chapter 3	Methodology	36
3.1	Introduction	36
3.2	Ontology and epistemology	37

3.3	The interpretivist theoretical perspective.....	38
3.4	Phenomenology	40
3.5	Other approaches considered.....	44
3.5.1	Narrative	44
3.5.2	Grounded Theory	45
3.6	Summary.....	46
Chapter 4	Methods	47
4.1	Introduction	47
4.2	Issues for consideration in retrospective research	47
4.3	Ethical considerations.....	49
4.4	Subjectivity and reflexivity	52
4.5	Research population.....	53
4.6	Recruitment of participants.....	53
4.7	Data collection procedure.....	55
4.8	Qualitative Interviewing	56
4.9	Field notes	59
4.10	Approaches to data analysis	59
4.10.1	Thematic analysis.....	60
4.10.2	Narrative structural analysis	62
4.10.3	Thematic structural analysis.....	62
4.11	Sampling thematic and narrative cases	65
4.11.1	Sampling for thematic analysis	65
4.11.2	Sampling for narrative structural analysis	67
4.12	Data analysis procedures	67
4.12.1	Preparing data for analysis: transcription	67
4.12.2	Application of data analysis.....	68
4.13	Issues of quality	73
4.14	Summary.....	76
Chapter 5	Introduction to the Findings Chapters	77

5.1	Demographics of study population	77
5.2	Whole sample demographics	79
5.3	Introduction to participants	84
5.4	Presentation of results and organisation of themes	101
Chapter 6	Findings I: Roles & Relationships	102
6.1	Participants' understanding of their role	102
6.2	Carers' responsibilities for care	102
6.2.1	Responsibility and decision making: blurred lines between family care and nursing care (as perceived by participants)	103
6.2.2	The difficulties of personal care	106
6.3	Carers' expectations of the roles of others	108
6.4	Carers as experts in person-centred care.....	111
6.5	Summary.....	118
Chapter 7	Roles & Relationships Part II: roles & place of care	119
7.1	Introduction to the model	119
7.2	The dynamics of care at home	121
7.3	Hospital	125
7.4	Hospice	130
7.5	Nursing home.....	135
7.6	Discussion of models and theory	136
Chapter 8	Findings II: Uncertainty and Reassurance.....	138
8.1	Introduction	138
8.2	The need for support	140
8.3	Care and support may improve at the end of life (compared to pre-end of life care) 142	
8.4	Access to care and support.....	144
8.4.1	The carers' 'fight' to access timely care and support.....	144
8.4.2	'Ring us if you need us': the problem of reactive care and support	147
8.4.3	Access to information, care and support: a case of luck and chance?	154
8.5	Continuity of care.....	157

8.5.1	Home	158
8.5.2	Hospital	165
8.5.3	Hospice.....	165
8.6	Uncertainty around pain and symptom management at the end of life	166
8.7	Feeling (un)prepared for the caregiving role	169
8.8	Feeling (un)prepared for the future	170
8.9	Employment and financial uncertainty	177
8.9.1	Employment.....	177
8.9.2	State benefits	181
8.9.3	Means testing for care and support, state benefits, and aids and adaptations 183	
8.10	Summary.....	185
Chapter 9	Findings III: Communication I.....	187
9.1	The need for information	187
9.2	Doctor/patient confidentiality can become a barrier to family caregivers gaining the information they need	191
9.3	<i>‘Dancing in the dark’</i> : the lack of information on the condition and the likely progression of the illness at diagnosis and in pre-end of life care.....	194
9.4	The value of end of life discussions for family carers	198
9.5	Optimising clinical interactions: considering the role of cultural health capital.....	207
9.6	Summary.....	212
Chapter 10	Communication II: Experiencing ‘care’ in caring: the importance of compassionate care	214
10.1	Introduction	214
10.2	Hospice care.....	215
10.3	Hospital care	217
10.4	Home care	219
10.5	Nursing and residential home care.....	220
10.5.1	Discussion	221
10.6	The continuing significance of kindness and compassion post bereavement	224

10.6.1	Summary	226
Chapter 11	Discussion and Conclusions	227
11.1	Discussion of the findings	227
11.1.1	Working towards co-ordinated care: implications of the study findings	230
11.2	Interactions between themes: the 'essence of experience'	231
11.3	Cancer and non-cancer patients	232
11.4	Discussion of findings in relation to research and policy	233
11.4.1	Research	234
11.4.2	Policy	234
11.4.3	Catalytic utility: implications for healthcare practice	236
11.5	Strengths of the study	237
11.5.1	Methodological strengths	237
11.5.2	Key findings	237
11.6	Limitations of the study	239
11.7	Findings in relation to models and theories of care	241
11.8	Proposed model of support arising from the data	241
11.9	Future research	242
	References	245
	Appendices	258
	Appendix 1: Notice of Ethical Approval	260
	Appendix 2: Participant Information Sheet	261
	Appendix 3: Consent Form	264
	Appendix 4: Interview Guide	265
	Appendix 5: Distress Protocol	266
	Appendix 6: Example of Field Notes	267
	Appendix 7: Example of Narrative Analysis	269
	Appendix 8: Code, Category and Theme Development	270

List of Figures

Figure 1: 'Typical illness trajectories for people with progressive chronic illness'.....	3
Figure 2: 'Appropriate care near the end of life'	4
Figure 3: Carers Direct webpage	10
Figure 4: NHS restructure (NHS 2013a)	12
Figure 5: Frequency of citations of 'carer' related terms in books published between 1975 and 2008	16
Figure 6: Major categories of good and bad interactions (Guo, Phillips & Reed 2010, pp. 336, reprinted with permission)	33
Figure 7: methodological perspective	37
Figure 8: methods of data analysis	60
Figure 9: NVivo 'tree node' structure.....	70
Figure 10: dyadic and triadic care relationships (Blair 2012, p. 1774)	120
Figure 11: Model of care proposed in this thesis	120
Figure 12: The interaction between formal and informal care at home.....	125
Figure 13: The interaction between formal and informal care in hospital	126
Figure 14: The interaction between formal and informal care in hospice	130
Figure 15: Balancing uncertainty and reassurance	140
Figure 16: The 'essence of experience'	232
Figure 17: Proposed model of support for carers and patients	242

List of Tables

Table 1: Example MeSH headings from Medline (Ovid)	17
Table 2: Example search Medline (Ovid)	20
Table 3: Search strategy	22
Table 4: Search terms used by Herber and Johnston (2012)	23
Table 5: Domains of caregivers' support needs	25
Table 6: Priority areas for family caregiver research (Hudson, Zordan & Trauer 2011, p. 399). Reprinted with permission.	35
Table 7: Source of recruitment.....	55
Table 8: Place of death by disease group	55
Table 9: sampling criteria	65
Table 10: NVivo terminology: adapted from Gibbs (2002)	69
Table 11: Establishing trustworthiness (adapted from Holloway & Wheeler 2010, pp. 302-304).....	75
Table 12: Sample Demographics.....	79
Table 13: Title and objectives of education intervention sessions (adapted from Hudson et al. 2008, p. 272).....	170
Table 14: Patient Rights (adapted from NHS constitution pg 45)	192
Table 15: Duty of Care (adapted from NHS constitution pg 107)	192

Chapter 1

Introduction

This chapter introduces the reader to the topic area, in order to provide a suitable context for the research study to be situated.

1.1 Study background

There are almost 5 million 'informal' caregivers in England, many of whom work for over 50 hours per week in their capacity as carer (Department of Health 2012a) and around 50,000 people die each year in England (Dying Matters 2013). A recent study by Macmillan estimated that there are over one million carers caring for a person with cancer in the UK (Macmillan Cancer Support & Ipsos MORI 2011). Many of these people are supported by both the health care system and by their family and friends. Most people would elect to die at home (Department of Health 2008b). However, where people die is heavily dependent on the health care services that are available to support them (Devlin & McIlpatrick 2010; Gomes & Higginson 2006).

The important role that family caregivers play in supporting people with chronic and life-limiting conditions has gained increasing recognition over the last decade. Family carers are now well recognised in academic literature and are supported by charities and government policy. For example, the present NHS website has a prominent tab named 'carers direct' on its homepage, linking visitors to a comprehensive range page of resources.

1.2 Definitions used in thesis

This section introduces the reader to the definitions of terms that are used throughout this thesis.

1.2.1 Defining 'formal' and 'informal' caregivers

There are a broad range of terms used in both academic literature and government policy to describe people who provide unpaid care and support to relatives or friends. These include 'informal', 'family', 'unpaid' or 'lay' 'caregiver' or 'carer'. The terms 'carer' and 'caregiver' are used throughout this study.

The following definitions are particularly useful and are adopted in this study. Both emphasise that a person's main carer is not restricted to family relationships;

'family members, friends and other people who have significant non-professional or unpaid relationships with a patient who they are caring for during advanced illness and the dying phase.' (Payne 2010, p. 238)

‘Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management.’ (NICE 2004 in Payne 2010, p. 239)

The terms ‘formal care’, ‘formal carers’ and ‘formal systems of care’ are adopted in this thesis to describe support from health and social care professionals. This includes, for example, GPs, district nurses, other clinicians, nurses in hospitals and carers provided through social services or private agencies, Macmillan nurses, Marie Curie nurses, any other palliative care specialist and all other paid professionals involved in a person’s care.

1.2.2 Stages of the illness trajectory

The duration of a person’s illness is commonly referred to as an ‘illness trajectory’. There are three main phases to an illness trajectory.

1. *Diagnosis* refers to a period of time where a person is undergoing an exploration of their illness and is then informed of their illness by a medical professional.
2. *Pre-end of life care* refers to care received between diagnosis and end of life.
3. *End of life care* refers to care that a person receives in the final days, weeks or perhaps months of a person’s life.

Different illnesses have different anticipated trajectories. This is usefully depicted in Figure 1.

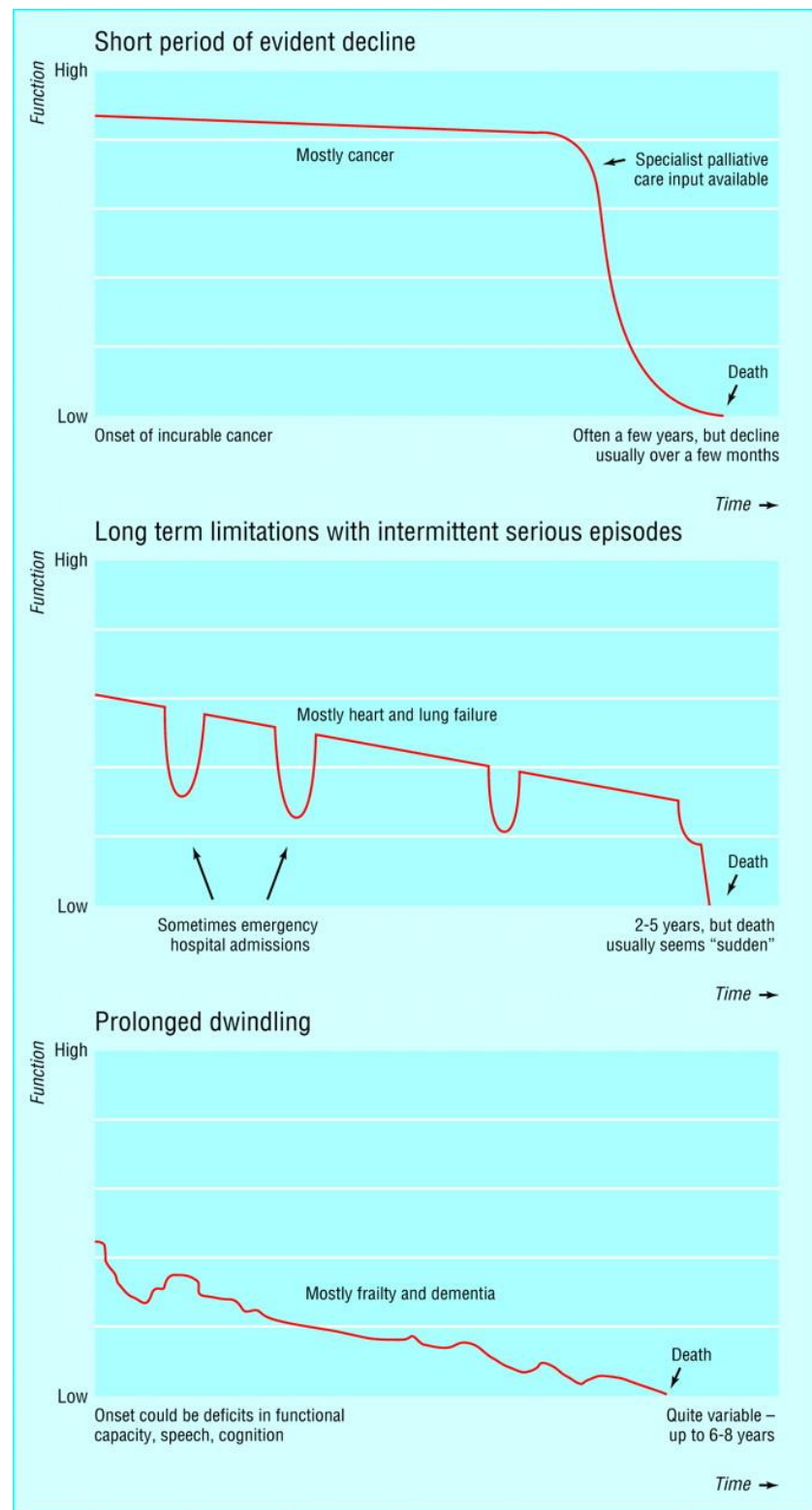


Figure 1: 'Typical illness trajectories for people with progressive chronic illness'

(Adapted from Lynn and Adamson, 2003. From (Murray et al. 2005). Reprinted with permission from BMJ).

People with life limiting illnesses may undergo a course of treatment which may be intended to either cure the disease (curative treatment) or to slow down the progression of the illness and extend a person's life (palliative treatment). Curative and palliative care may also take place concurrently (see Figure 2).

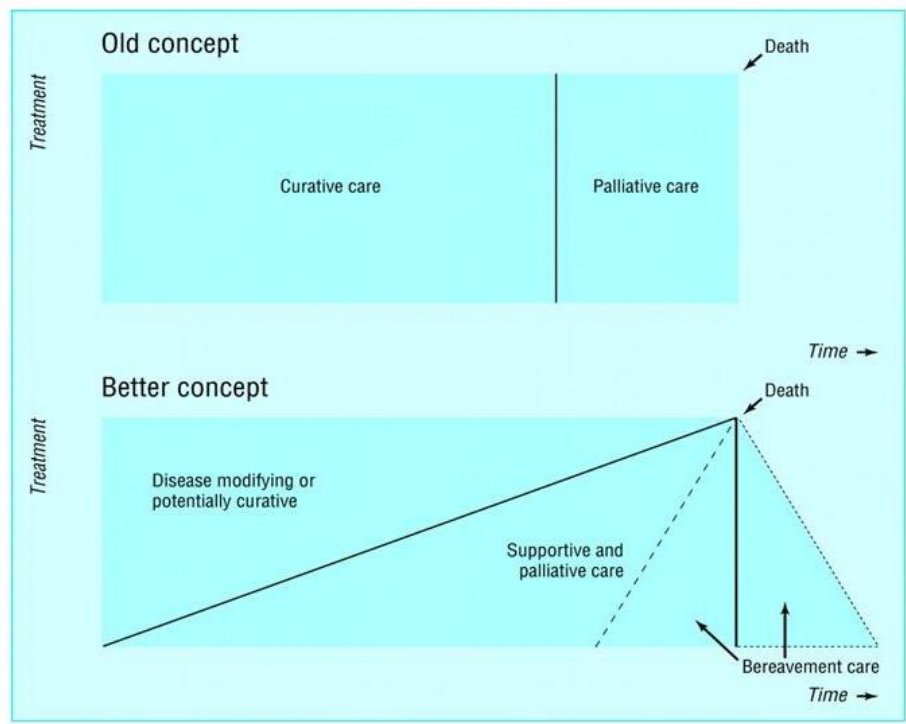


Figure 2: 'Appropriate care near the end of life'

(Adapted from Lynn and Adamson, 2003. From (Murray et al. 2005). Reprinted with permission from BMJ).

1.2.3 Life-limiting illness

This study focuses on carers of people who have life-limiting conditions. Life-limiting illnesses are illnesses that shorten people's lives (Cumbria and Lancashire End of Life Care Network & NHS 2011). Some life-limiting illnesses may also be classified as chronic illnesses, which the World Health Organisation (WHO) defines as 'diseases of long duration and generally slow progression' (World Health Organisation 2013). Examples of chronic diseases that are also life-limiting illnesses include, but are not limited to, some cancers, chronic respiratory diseases (COPD) and diabetes.

1.2.4 Palliative care

This study looks at care throughout the illness trajectory; from diagnosis through to end of life, death and bereavement. End of life care is often referred to as 'palliative care'. There are many definitions of palliative care, however, the definition offered by the European Association for Palliative Care is particularly useful as it provides an up to date definition with a European focus.

'Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount.

Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital.

Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death'. (European Association for Palliative Care 2010)

1.3 Supporting family caregivers: current policies and practice

It is useful to situate this study within the context of current government policies and initiatives (Oliver 2008). In recent years family carers have been increasingly recognised in and supported by government policies. This section briefly notes the historical and political context in which the study is situated, before introducing key policy documents in supporting family caregivers. Key resources from the public sector and charities are also discussed.

It is useful to note the change in government that occurred during the undertaking of this thesis. This change came at a key time for policy around end of life care. The discussion below notes which government the policy or document was published under.

1.3.1 National strategy

Since 2008 a number of key government publications have emerged which address the provision of care and support and end of life care issues. More recently, the formation of the Coalition government in 2010 led to major reform in health and social care provision. This section highlights key health and social care policies published between 2008 and 2013.

'High Quality Care for All', or 'the Darzi review' as it is often referred, was published in 2008 by the former Labour Government (Department of Health 2008c). The report set out to improve the quality of care received by all patients. The Darzi report emphasised 'quality at the heart of everything we do' (p. 47) and recognised patient experience as being central to achieving quality care. Providing patients with greater choice and more information were key recommendations from Lord Darzi's report. The Darzi report is significant to this thesis as it is the first government report to emphasise patient choice. An example of this includes the

piloting of a 'personal health budget' initiative, which aims to give patients and carers control of their own care and support.

Furthermore, the Darzi report emphasised the importance of the relationships between people with long term conditions and the professionals caring for them. The report highlighted 'personal care plans' and improved information for patients to help achieve this. The report also highlighted end of life services as an area for improvement, particularly around dignity in care and the recognition of the need for 24 hour access to palliative care services (Department of Health 2008c).

Published under the previous Labour government, 'Carers at the heart of 21st century families and communities' (Department of Health 2008a) set out the government's plans to support informal carers. The strategy was later reviewed and updated in the 2010 publication 'Recognised, valued and supported; next steps for the Carers Strategy' (Cross-Government Publication 2010). This report proposed an additional £4 million budget for the NHS and outlined a four year plan that specifically aimed to improve the quality of life of family carers in England. The report focuses on four key areas:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
- Enabling those with caring responsibilities to fulfil their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

(Cross-Government Publication 2010, p. 6)

Also published in 2008, the Labour government published the 'End of Life Care Strategy', which set out to provide 'the first comprehensive framework aimed at promoting high quality care across the country for all adults approaching the end of life' (Department of Health 2008b, p. 7). The strategy identified twelve key areas of focus for improving end of life care in England and committed to make £88 million available for Primary Care Trusts (PCTs) to invest in end of life care in 2009/10 and a further £198 million in 2010/11 (Department of Health 2008b). The strategy set out to improve access to services; coordinated care and support for all patients, irrespective of place of care or transitions between places of care; specialist end of life services that are easily accessible to carers and patients and dignified

care at all stages and excellent care at the end of life (ibid). The report states that these objectives would be achieved through investing in education and training for staff and improved access to services for the palliative population (ibid). Furthermore, the report asserts that carers would be supported throughout the end of life, with hospitals providing facilities to enable carers or relatives to stay overnight (ibid).

Established in 2001, The Gold Standards Framework provides evidence based guidance to facilitate health professionals to deliver care to people with an end stage illness, including people who are nearing the end of life and across all care settings (National Gold Standards Framework Centre 2012). The framework provides the basis for training generalist staff in end of life care (The Gold Standards Framework 2013).

The National End of Life Care Programme (NEoLCP) was set up in support of the government's End of Life Care Strategy and is backed by £286 million pounds. It aims to 'promote high quality, person-centred care for all adults at the end of life' and 'enable more people nearing end of life to choose where they live and die' (NHS 2013b). The programme primarily aims to provide recourses for health and social care staff, but there are also links to support for members of the public.

Since the formation of the coalition government in 2010, several key documents have been published, aiming to reform health and social care in the UK. In July 2010 the Department of Health published the white paper 'Equity and excellence: liberating the NHS' (Department of Health 2010). This document proposed major reforms in the NHS. The main changes have taken place in primary care; 'Primary Care Trusts' (PCTs) and 'Strategic Health Authorities' (SHAs) have been replaced with 'Clinical Commissioning Groups' (CCGs), which consist of a number of GP services pooling resources to procure services and manage their own budgets (NHS 2013c). These changes are depicted in Figure 4.

Recognising and supporting family caregivers remained on the new government's agenda; published in July 2012, 'Caring for our future: reforming care and support' (Department of Health 2012a) claims that the current care and support system is 'broken' and proposed major reforms in order to make a service fit for the 21st century aging population (p. 3). The document sets out the coalition government's intention to reform care and support services over a ten year period. The coalition pledged to spend £100 million in 2013/2014 and a further £200 million in 2014-15 to support a better integrated system of care and support between the NHS and other areas of social care (Department of Health 2012a, p. 11). It argues that reform will greatly improve access to services as well as the quality of services for all patients and carers. The report's main areas of focus are greater support from local

communities for carers and those being cared for; better and more transparent information for carers; improved quality of care; and dignity in care provision. The document proposes to provide all people who require care and support with a personal budget. A 'personal budget' allows people to purchase the specific services that they require, giving individuals greater control over their care and support. This initiative is currently being piloted.

This white paper represents a major step forward in addressing many of the fundamental issues in care and support services. The issues addressed in this document reflect those that are well rehearsed in the academic literature in this area, and indeed the main areas of concern in this study. The paper was published during the data analysis stage of the PhD study. Every effort has been made to incorporate the findings of this publication, although inevitably, the scheduled release of more detailed information on aspects of the paper will affect the impact, power and relevancy of the findings. Nevertheless, this publication provides substantial evidence to suggest that the findings presented in this thesis are representative of a wider population of carers in England. The white paper calls for a shift in the culture of care and support, not just a shift in policy and practice. Future research may help to determine whether this aim is achieved.

The ideology of the coalition government is somewhat different to that of the previous Labour government. The current government promotes what it refers to as the 'Big Society'. This initiative promotes action and power in local communities, as opposed to the state. An example of this is to roll out the pilot of personal care budgets; giving individuals the power to purchase the care they feel is right for them. In contrast, the previous Labour government tended to focus on centralised, state run services.

Following the End of Life Care Strategy's commitment to monitor and improve services for patients and carers the Department of Health recently commissioned an initiative that aims to monitor patient experience and measure the quality of end of life care, as reported by bereaved informal carers. The 'Views of Informal Carers Evaluation of Services' (VOICES) report builds on the ideas presented in the afore mentioned documents by recognising the important role that family carers play, and promotes better end of life care through monitoring services (Department of Health 2012b). This initiative is significant to this thesis as it draws on the views and experiences of bereaved family caregivers in assessing the quality of care in different care environments and over time.

It is notable that much of the current guidance and policies are specifically focused on the last year of life and end of life care.

At the time of writing, the NHS 'Choices' website has a prominent tab on its homepage named 'Carers Direct' (see Figure 3). Carers Direct has a wealth of resources for people who provide unpaid care and support for another person in England; it provides information on many aspects of caring as well as prominent links to direct support and a searchable database of information on local services. This website therefore provides an example of putting policy into practice; it emphasises choice in health and social care, improves access to services by pointing visitors to the correct area of the website or to external links, and improves access to information in the digital age of the 21st century.

This chapter has outlined the important role that family carers play in providing unpaid care and support for others has gained increased recognition by successive governments. The policies and strategies that have come to the fore in recent years signify a step forward in attempting to improve the lives of carers and patients and in tackling some of the fundamental issues in providing unpaid care for a loved one.

Recent changes to guidelines and policies indicate that the government has indeed provided improved access to information and services for people with life limiting illness and their informal caregivers. However, it could be argued that the true measure of the success of the strategies and policies identified above is through listening to the *experiences* of informal carers; have the changes brought about as a result of these policies made a real difference to family carers? Future research will play an important role in assessing the impact of these policies on the quality of care received by patients and the perceived quality of support provided to family caregivers.

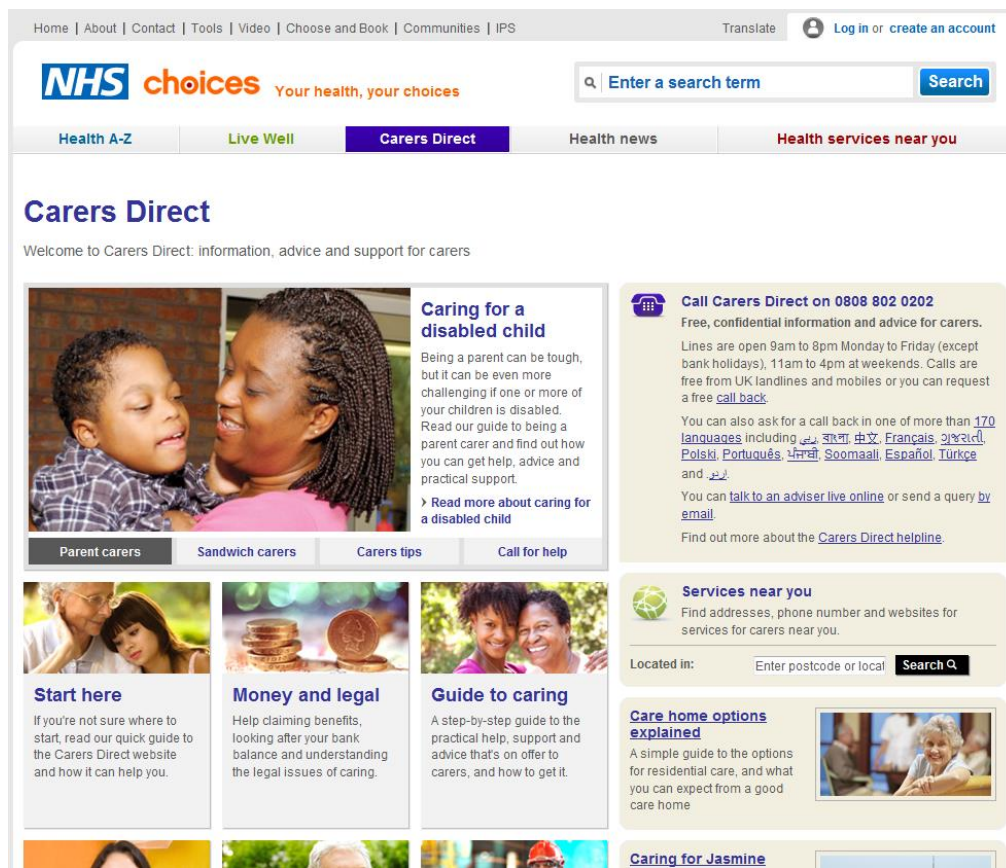


Figure 3: Carers Direct webpage

1.3.2 Regional strategy

This thesis was written during a period of major reform in the NHS. Such reforms will inevitably effect how care and support services are provided at a local level, as well as the wider health care structure. Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) were/are fundamental to the delivery of health policies at a regional level prior to the reforms brought about by the coalition government. At the time of writing, PCTs and SHAs are being disbanded and being replaced by GP commissioning consortia, who will procure services at a local level. The implementation of the new service structure is likely to vary between areas.

The ethos behind the new structure is an increased emphasis on care in the community. This is significant when considering that many people would choose to be cared for and die at home (Agar et al. 2008; Higginson & Sen-Gupta 2000). In 1995, evidence suggested that the care provided by family caregivers saves the UK government approximately £40 billion a year (British Medical Association 1995, reported in Nolan 2001). This figure is likely to be far greater today. Evidence also suggests that care in the community also has cost savings when compared with in-patient hospital care (Brumley et al. 2007), although a recent

systematic review has found claims regarding cost benefits to be inconclusive (Gomes et al. 2013). This is an important factor when we consider the drive for efficiency savings and cutbacks within the NHS.

Figure 4 demonstrates the restructure of the health and social care system implemented in April 2013.

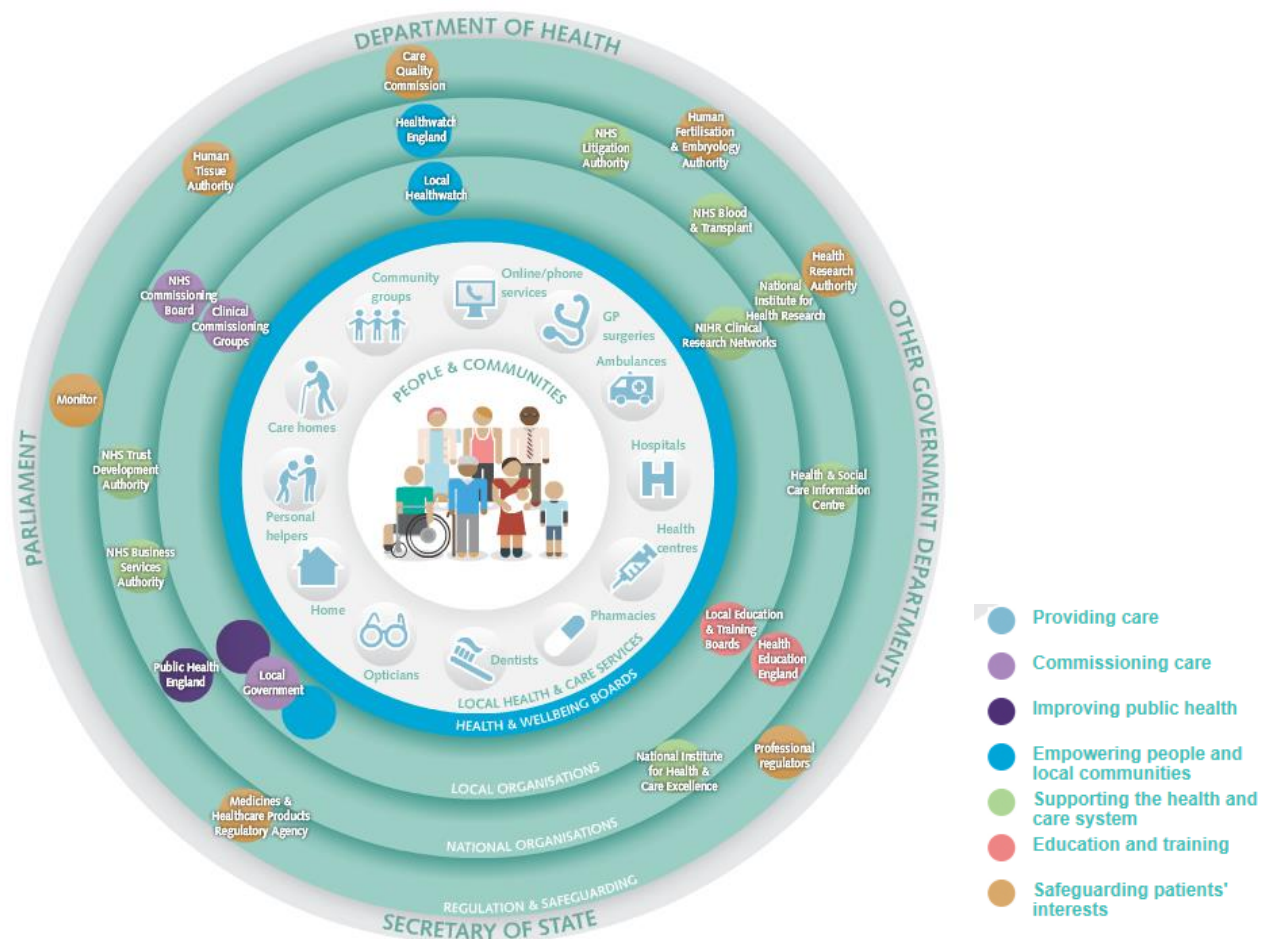


Figure 4: NHS restructure (NHS 2013a)¹

¹ An interactive version of Figure 4 is also available from the Department of Health website <http://healthandcare.dh.gov.uk/system/>

1.4 My personal interest in this area

In September 2009 I took part in an overseas fundraising event to raise money for a local hospice. My grandmother was cared for at the hospice some years earlier and, more recently, the partner of a close friend was also cared for in the hospice. I enjoyed getting to know the other trek participants over the five day excursion; listening to people's experiences of being a family member, friend, or staff member at the hospice. The experience of taking part in this trek and the stories I heard had a profound effect on me.

During this time I was also enrolled on a Master of Research (MRes) in Health Sciences. My interests in end of life care and background in research led to me pursuing a post as a research assistant at the University of Liverpool, in the Academic Primary and Supportive Care Research Group, where I later had the opportunity to embark on this PhD.

1.5 Developing the research question

Research in supporting family caregivers was topical and current; the government had recently published a number of key policy documents regarding end of life and palliative care, which had explicitly recognised the important role that family caregivers undertake when caring for a relative with a life-limiting illness (these policy documents are detailed earlier in this chapter).

During the course of the PhD I took part in postgraduate qualitative data analysis sessions, where students have the opportunity to present their research and extracts of their data. Preliminary ideas were discussed and developed in one such session and the research question was amended to explore the experiences of family carers of people with a life-limiting illness throughout the illness trajectory. The research question asks: *how do systems of formal and informal care work together to meet the needs of carers and patients throughout the illness trajectory?*

1.6 Introduction to chapters

This chapter has introduced the key issues and concepts central to this study. Key policy documents in this area have been outlined in order to provide background and context for this study. The rationale for the study has also been discussed. Chapter two introduces key themes from the academic literature in this area, providing further context for the setting of this study. The methodology chapter (chapter three) discusses the epistemological, philosophical and theoretical background that underpin this study, whilst chapter four outlines and justifies the methods adopted in gathering and analysing data. Chapter five introduces the main findings chapters and provides the reader with vignettes of the participants who took part in this study. These vignettes provide further context to the findings that are

discussed in the subsequent chapters, which the reader may wish to refer back to when reading the findings chapters.

Chapters six to nine present the main research findings. In accordance with the approach to data analysis, the chapters are presented thematically. Chapter six explores the theme of roles and relationships. This theme examines the role that family carers undertake and family carers' expectations of the roles of health and social care professionals. Chapter seven expands on this theme by examining the place of informal care and support (provided by families) and formal care and support (care provided by health and social care professionals) in different places of care (home, hospital and hospice). In this chapter, current models of care are discussed and new models of care, demonstrating the interactions between informal and formal care, are proposed. These models are borne out of the research findings from this study. Chapter eight focuses on the theme of uncertainty and reassurance. The chapter draws upon Mishel's uncertainty theory to aid the interpretation of key findings. The chapter also draws upon the work of Alfred Schuetz and his notion of 'the stranger' in relation to carers' experiences of care and support from community based health and social care. The final theme, communication, is presented in two parts. Part one (chapter nine) focuses on the verbal and non-verbal communication in the interactions between systems of formal and informal care. The findings are discussed with reference to Bourdieu's notion of 'cultural capital'. The second part of the communication theme (chapter ten) focuses on kindness and compassion in care interactions and how this is communicated, interpreted and understood by family caregivers.

The final chapter (chapter eleven) summarises the key findings of the study and discusses these in relation to research, government policy and clinical practice in this area. The strengths and limitations of the study are discussed and the study's original contributions to knowledge outlined.

Chapter 2

Literature Review

2.1 Introduction

Commenting on the overview of literature in the field in 2001, Jones argued that existing reviews often typecast informal caregivers:

'Broadly, the person who has emerged from much of this literature is an automaton who lifts, toilets, washes, medicates, cleans, shops, feeds, watches over and, most of all, worries.' (Jones 2001: 18)

This review seeks to go beyond a description of the practical aspects of caring for a family member with a life-limiting illness and provide a detailed and critical overview of the literature in the area.

This critical overview is the result of a scoping exercise, rather than a systematic review. As such, it was not deemed necessary to assess the articles identified through the search strategy to a quality appraisal, such as the Critical Appraisal Skills Programme (CASP), for example (Critical Appraisal Skills Programme 2014).

2.2 The search strategy

The literature on informal caregiving and the experiences of informal caregivers is vast. The area of study gained increased recognition in the 1980s, with perspectives offered from psychology, sociology and health services research amongst others. Figure 5 provides a useful illustration of this; it depicts the frequency that the terms 'family caregivers', 'carers' and 'family carers' occur in books published between 1975 and mid 2007 (information was not available past 2007).

The vast amount of literature in this area necessitated a thorough and methodical search strategy. Key terms relevant to the study were initially identified using the 'subject term' search facility on EBSCO Host: Academic Search Complete. Medline was used to identify medical subject headings (MeSH headings) before an appropriate search was conducted. This tool enables the user to identify 'catalogued' terms used in that database, therefore illuminating the need to use many variations of a word or phrase to identify appropriate articles. Table 1 provides a list of the MeSH terms that were identified and incorporated in the search strategy.

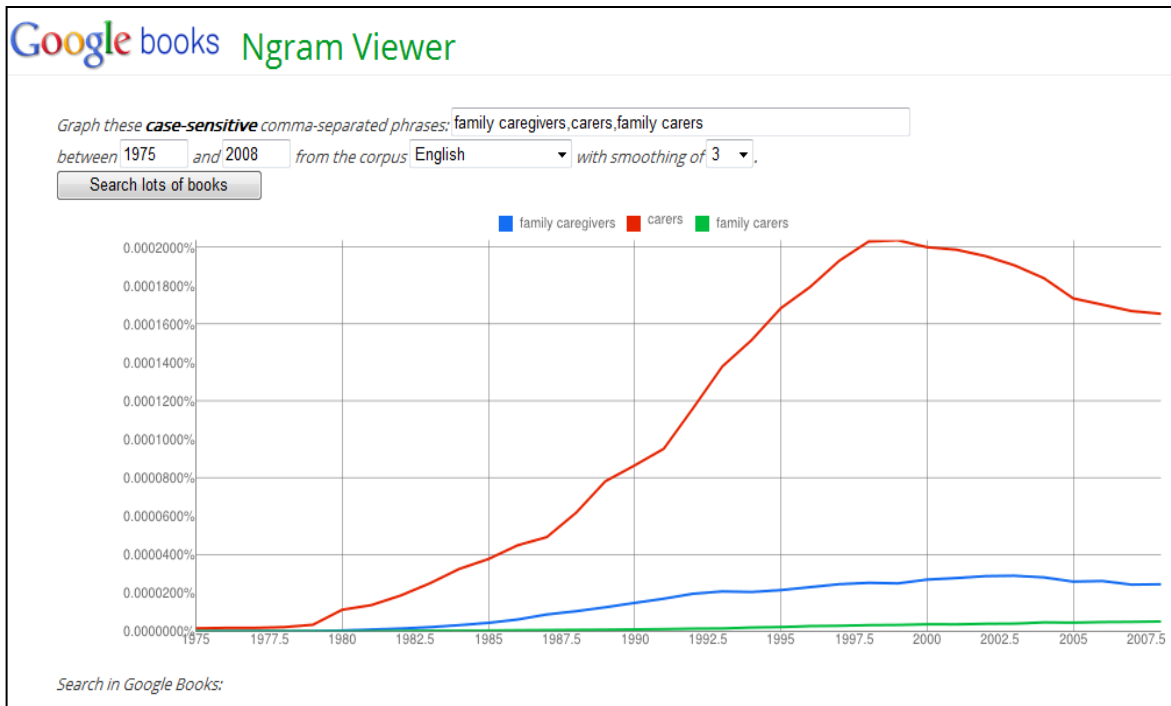


Figure 5: Frequency of citations of 'carer' related terms in books published between 1975 and 2008

Table 1: Example MeSH headings from Medline (Ovid)

MeSH Term	Used for	Scope notes
Caregivers	family caregiver; care givers; caregivers; caregivers spouse; caregiver family; caregiver; family caregivers; spouse caregivers; care giver; spouse caregiver; caregiver spouse; carer; caregivers family; carers	Persons who provide care to those who need supervision or assistance in illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although caregivers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients.
Chronic disease	chronic illnesses; illness chronic; chronically ill; diseases chronic; illnesses chronic; chronic illness; disease chronic; chronic disease; chronic diseases	Diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care. (Dictionary of Health Services Management, 2d ed)
Social support	support system psychosocial; support social; psychosocial support systems; network social; social support; system psychosocial support; psychosocial support system; networks social; social network; systems psychosocial support; support systems psychosocial; social networks	Support systems that provide assistance and encouragement to individuals with physical or emotional disabilities in order that they may better cope. Informal social support is usually provided by friends, relatives, or peers, while formal assistance is provided by churches, groups, etc.
Palliative care	medicine palliative; surgery palliative; palliative surgery; therapy palliative; palliative care; treatment palliative; palliative therapy; palliative medicine; care palliative; treatments palliative; palliative treatment; palliative treatments	Care alleviating symptoms without curing the underlying disease.
Terminal care	care end life; life care ends; care	Medical and nursing care of patients in the terminal stage of an illness.

	terminal; terminal care; end of life care; life care end; care ends life	
Home care services	domiciliary care; care services home; home care service; services home care; home care; service home care; home care services; care domiciliary; care home	Community health and NURSING SERVICES providing coordinated multiple services to the patient at the patient's homes. These home-care services are provided by a visiting nurse, home health agencies, HOSPITALS, or organized community groups using professional staff for care delivery. It differs from HOME NURSING which is provided by non-professionals.
Hospitals	hospital; hospitals	Institutions with an organized medical staff which provide medical care to patients.
Hospice care	hospice programs; programs hospice; care hospice; program hospice; hospice care; care bereavement; hospice program; bereavement care	Specialized health care, supportive in nature, provided to a dying person. A holistic approach is often taken, providing patients and their families with legal, financial, emotional, or spiritual counseling in addition to meeting patients' immediate physical needs. Care may be provided in the home, in the hospital, in specialized facilities (HOSPICES), or in specially designated areas of long-term care facilities. The concept also includes bereavement care for the family. (From Dictionary of Health Services Management, 2d ed)
Hospices	hospices; hospice	Facilities or services which are especially devoted to providing palliative and supportive care to the patient with a terminal illness and to the patient's family.
Community health services	health services community; community healthcare; community health care; community healthcares; community health services; care community health; services community health; health care community; health service community; healthcare community; service community health; healthcare community; community health service	Diagnostic, therapeutic and preventive health services provided for individuals in the community.
Community health nursing	nursing community health; community health nursing	General and comprehensive nursing practice directed to individuals, families, or groups as it relates to and contributes to the health of a population or community. This is not an official program of a Public Health Department.

Interpersonal relations	<p>husband-wife communications; social interactions; gender issue; communication husband- wife; interpersonal relation; communications husband-wife; relations interpersonal; partner communication; gender relations; relations gender; interpersonal relations; relation gender; communication partner; partner communications; social interaction; issue gender; gender relation; gender issues; communications partner; relation interpersonal; husband- wife communication; husband wife communication; interaction social; issues gender; interactions social</p>	The reciprocal interaction of two or more persons.
Delivery of health care, integrated	<p>delivery of health care integrated; system integrated delivery; delivery system integrated; delivery systems integrated; integrated delivery system; integrated health care systems; systems integrated delivery; integrated delivery systems</p>	<p>A health care system which combines physicians, hospitals, and other medical services with a health plan to provide the complete spectrum of medical care for its customers. In a fully integrated system, the three key elements - physicians, hospital, and health plan membership - are in balance in terms of matching medical resources with the needs of purchasers and patients. (Coddington et al., Integrated Health Care: Reorganizing the Physician, Hospital and Health Plan Relationship, 1994, p7)</p>

The search strategy was developed using these MeSH headings. An example of which is outlined in Table 2:

Table 2: Example search Medline (Ovid)

Searches	Terms used	Results
1	Caregivers	21759
2	Chronic disease	220844
3	Social support	51886
4	Palliative care	40643
5	Terminal care	21388
6	Home care services	27825
7	Hospitals	53230
8	Hospice care	4668
9	Hospices	4384
10	Community health services	27041
11	Community health nursing	18408
12	Interpersonal relations	55878
13	Delivery of Health Care, Integrated	8498
14	1 AND 2	838
15	5 OR 6	57062
16	6 OR 10 OR 11	67301
17	12 OR 13	64359
18	14 AND 17	35

Standard boolean operators such as 'AND', 'OR', and 'NOT' were used to widen or narrow search results. Truncation '*' was also used to search for words with variant endings e.g. 'care*' would elicit results for 'carers', 'care giver', 'caregiver', and plurals of these words.

Databases searched included Medline, Scopus and Web of Knowledge. Literature was also gained through Google Scholar, RSS feeds, email alerts, peers working in the same area and following up references from conferences and other publications.

Many results included caring for disabled children, or children and young people caring for an adult family member. It was not possible to exclude these papers in the first instance, as

many did not specify 'adult' or 'children' as keywords. These articles were identified manually and excluded from the review.

Search results from Medline yielded few results. It was therefore necessary to expand the search to social science databases, such as PsycINFO, ASSIA and Scopus. Some social science databases did not recognise MeSH terms, therefore keywords were identified from existing papers before searches were conducted. Other databases (such as the British Nursing Index) do not catalogue or standardise keywords using this system. In cases such as this MeSH terms formed the basis for the search, with other terms being identified and added to further expand the search. The strategy of combining MeSH terms with non-MeSH terms is outlined in Table 3.

Search results were imported into the reference management software Endnote X5 and duplicate entries were deleted.

The search was refreshed on a number of occasions during 2010-2013 in order to keep up to date with current literature in the area. The publication of a systematic review in 2012 (Herber & Johnston 2012) identified approximately thirty different terms for professionals who may be described as formal caregivers, as well as multiple terms for end of life care, place of care and patient group (see Table 4). Subsequent searches utilised the search terms detailed in this publication in order to retrieve optimum search results and minimise literature (particularly international literature) being missed.

Table 3: Search strategy^{2 3}

AND	OR								
	CAREGIVERS	FAMILY	Carer*	Family carer*	Caregiver*	Family caregiver*	Lay care*	Family support	Informal care*
	Health professional*	Healthcare professional*	Health-care professional*	Care assistant	Health-care assistant	nurse	GP	Formal care*	Home help
	CHRONIC DISEASES	Life-limiting	Life limiting	Progressive illness	Terminally ill	NEUROLOGICAL	NEOPLASMS	RESPIRATORY	
	TERMINAL CARE	PALLIATIVE CARE	end of life care	End-of-life	End-of-life care				
	SOCIAL SUPPORT								
	HOME CARE SERVICES	COMMUNITY HEALTH SERVICES	COMMUNITY HEALTH NURSING	Home					
	HOSPITALS	Hospital*							
	HOSPICE CARE	Hospice*							
	Nursing home	Residential home							
	PLACE OF DEATH								
	SOCIAL INTERACTION	Relationship*	Interaction*	Dyadic	Triadic				
	INTEGRATED DELIVERY OF CARE	Co-ordinated care	Coordinated care						
	Systematic review *	Review	Literature review	Review of literature					
	Retrospective								

² Table adapted from University of Liverpool Library workshop

³ Terms in capitals denote MeSH terms. Terms in lowercase denote standard keyword search.

Table 4: Search terms used by Herber and Johnston (2012)⁴

Search terms for HCSW	Search terms for end-of-life-care	Search terms for setting	Search terms for patient group
Ancillary staff; Auxiliary nurses; Care assistant; Care support worker; Care workers; CNA; Community support worker; Domiciliary care assistants; Health auxiliary; HCA; Health care assistant; Health care support workers; Healthcare aid; Home health aid; Home health aid services; Home health aids; Home helper; Home-care support worker; Home-care worker; In-home supportive services; LPN; Nurse aid; Nurse assistant; Nurse helper; Nursing assistants; Nursing home personnel; Registered nursing assistants; Social carer; Unqualified aids	Care of dying; Care of the dying; Edge of life; End of life; End-of-life-care; Palliative care; Palliative; Palliative therapy; Supportive care service; Support care; Supportive care; Terminal care	Care in the community; Community health services; Home; Home care; Home nursing care; Home-based care; Nursing home; Residential care	Life-limiting illness; Progressive, Terminally ill

[CNA, Certified nursing assistants; HCA, Health care aids; HCSW, Health Care Support Worker; LPN, Licensed practice nurse.]

2.3 The needs of carers of people with life-limiting illnesses

Much of the literature focuses on identifying the needs of carers providing home-based care. This is largely due to the changes in health and social care policy and practice (Payne, Smith & Dean 1999) and an increased recognition of patients' preference to be cared for and to die at home (Gomes, Calanzani & Higginson 2011; Higginson & Sen-Gupta 2000).

The supportive needs of family caregivers broadly fall into two areas. These are emotional (psycho-social) support and information support needs. Emotional or psycho-social support includes, for example, bereavement support, coping skills, and support relating to a person's wellbeing (such as anxiety or depression). Support needs relating to information include, for example, information about how to manage a person's symptoms, the likely progression of the illness, and information about death and dying. It is useful to draw upon several key studies in this area to provide further detail on the needs of carers of people with life-limiting illnesses.

⁴ (Table adapted from Herber and Johnston, 2012 p.3)

In a systematic review of informal caregivers' needs in providing home based care to people with cancer, Bee, Barnes and Luker (2009) report a dearth of information relating to practically-focused information for carers. The authors assert the need for further interventions to be designed and tested to meet this need. However, this review focuses solely on the needs of carers of people with cancer and does not relate these findings to carers providing home-based care to relatives with other life-limiting illnesses.

Hudson (2004) notes that the findings of his study on caregivers' needs identified 'poor continuity, inadequate information, limited respite, lack of symptom management education and health professional role related issues' (p. 63). He highlights that these issues are not new and have been highlighted 'consistently' in the literature in this are 'over the past two decades' (p. 63). It is problematic that such issues remain so prevalent, given the large amount of research conducted in this area. It is also interesting that similar issues are experienced by carers in numerous different countries (Hudson's work is undertaken in Australia, for example). This suggests that there are issues around caring as a phenomenon that remain unaddressed, rather than something that is specific to a particular disease, policy or country, for example. This study will take this into account by addressing caregiving as a phenomenological experience.

The Carer Support Needs Assessment Tool (CSNAT) was developed as a means of assessing carer support needs in end of life care at home. This tool is evidenced based and was developed from the findings of qualitative research involving focus groups and telephone interviews with 75 bereaved family caregivers (Ewing & Grande 2012). The authors identified two key areas of support needs: support to help carers better care for their relative, and direct support needs of carers. The sub categories are listed in Table 5 (overleaf). Further detail on each of the items are provided in the original paper (Ewing & Grande 2012). The tool has since been validated for use in palliative and end of life care at home (Ewing et al. 2012).

The research underpinning the development of the CSNAT has particular significance to this section of the literature review, as it focuses on the needs of carers of people in the palliative phase rather than being disease specific, and the research was conducted in the UK. Other scoping tools, such as the CNAT-C (Shin et al. 2011), have also been developed. The CNAT-C was developed for a population of cancer caregivers in Korea. To date, the tool has not been validated in the UK.

The advanced literature search conducted for the purpose of this chapter (detailed earlier) revealed that much research in this area is disease specific or specific to a particular stage of the illness trajectory, making it difficult to produce a coherent summary. Disease or stage

specific research is important, as this research addresses needs that are tailored to a particular population, but there is a dearth of research that considers the similarities and differences between the needs of carers of people with life-limiting illnesses. Furthermore, the commonalities in the needs that are reported in these reviews indicate that there are underlying issues in care and support which appear to remain unaddressed.

Table 5: Domains of caregivers' support needs

(Adapted from Ewing & Grande 2012)

Support to help carers better care for their relative	Direct support for carers
<ul style="list-style-type: none"> • Having a named support contact • Managing the patient's symptoms and medicines • Support with equipment • Providing personal care • Support to understand the illness • Support to understand the dying process • Talking with the patient about the illness • Support at the time of death 	<ul style="list-style-type: none"> • Respite support • Physical health concerns • Financial and work issues • Practical support • Emotional support

2.4 Interventions to support family carers

Research in this area is now moving away from identifying carers' needs to promoting identifying, designing and testing appropriate and effective interventions to support carers (Grande et al. 2009; Harding & Higginson 2003; Hudson, Aranda & McMurray 2002; Hudson, Zordan & Trauer 2011). Supportive interventions for carers broadly address the needs outlined in the previous section.

The Cochrane Collaboration offer a systematic review of interventions aimed at supporting informal caregivers of people in the terminal phase of a disease (Candy et al. 2011). The review includes interventions that aimed to provide practical or emotional support, or to facilitate coping skills. Eleven studies (equating to 1836 caregivers) were identified as meeting the inclusion criteria and were included in the review. Of the eleven interventions, nine were delivered directly to the carer, and two were indirect supportive interventions, delivered to the patient. Seven of the interventions delivered directly to caregivers focussed on supporting carers in their role by facilitating coping skills (seven trials) and improving wellbeing (two trials). The review highlighted the absence of interventions that provided

practical home support. The two trials that aimed to improve outcomes for family caregivers through indirect interventions both did so by providing support to the patient.

The effectiveness of interventions are commonly measured by assessing differences in outcome measures between intervention and non-intervention groups. Findings from the review suggest that supportive interventions provided to family caregivers resulted in significantly reduced psychological distress and some (non-significant) improvement in coping and quality of life measures. The authors note that these findings are derived from low quality evidence, therefore making it difficult to draw specific conclusions. Generally speaking however, the authors note that emotional support and information regarding managing their relative's care were key features of the interventions and are likely to safeguard against psychological distress (Candy et al. 2011).

This systematic review is useful as it summarises the breadth of interventions that are being developed in this area of research and evaluates the effectiveness of the interventions. It is of note that although this review was not disease specific, ten of the eleven studies focussed on caregivers of people with cancer. This suggests that addressing the needs of caregivers with a non-cancer diagnosis are under-represented in high quality randomised controlled trials.

Caress, Chalmers and Luker (2009) present a systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. The review synthesized the findings of nineteen interventions, and concluded that more robust evaluations of interventions were needed.

A review of psychosocial interventions for family carers of palliative care patients, for example, synthesised the findings of fourteen studies that were published between 2000 and 2009 (Hudson, Remedios & Thomas 2010). Interventions included psycho-educational, psychosocial support, coping, symptom management, sleep promotion and family meetings and included both quantitative and qualitative studies (ibid). The review confirmed that there was an increase in the number and quality of psychosocial interventions undertaken over this decade, but asserted the need for further improvements in this area of research, noting that 'there are still significant improvements to be made in terms of the number, rigor and design of future studies' (p. 4).

In order to design and implement effective supportive interventions for family caregivers it is important to investigate the barriers that health professionals may face regarding the feasibility and acceptability of the care environment in which they work, as well as the resources available within a service (Hudson, Aranda & Kristjanson 2004). Hudson, Aranda

and Kristjanson (2004) undertook such research with palliative care health professionals in Australia. The findings uncovered a range of family and health system related barriers that may raise challenges for effective interventions. Gaining an understanding of the needs of carers as well as the perspectives of health professionals may lead to better informed intervention designs.

It is important that the outcomes of interventions are appropriately evaluated in order for the effectiveness of the interventions to be assessed. Holickly (1996) further identifies that evaluations of interventions should address the 'optimal type of support offered, length of intervention and attendance and understanding of ethnic differences in acceptability and effectiveness' (Holickly 1996 in Harding & Higginson 2003, p. 71). One systematic review, for example, reported that only six out of twenty-two interventions identified were evaluated (Harding & Higginson 2003).

The research literature on interventions in palliative and supportive care is diverse. However, much research is disease or context specific. Whilst it is important to address and meet the needs of specific groups, there are likely to be some common issues and needs which are shared by the population of carers of people with life-limiting illness.

2.5 The 'burden' of care

Informal caregivers play an integral part in the daily lives of the people they care for, from help with physical tasks to emotional support and the monitoring of symptoms, general health and wellbeing as well as their existing roles and relationships of family members and friends. Such increased responsibilities, in addition to, existing family or work commitments may strain family relationships.

The complexities of emotional, practical and physical responsibilities are often referred to as 'carer burden' or the 'burden of care' in the literature. This relates to the often changed circumstances families find themselves in when a loved one becomes chronically ill. A person's illness may affect many aspects of family life, such as employment, income, travel, time, and other family dynamics. These may be broadly themed as having psychosocial, occupational and economic dimensions (Grunfeld et al. 2004).

Lorenz et al. (2008) identified nineteen intervention studies and eight systematic reviews focusing on caregiver burden at end of life. The authors interestingly note that much of the literature in this area is concerned with dementia caregivers and, to a lesser extent, carers of people with cancer⁵. A synthesis of the data revealed that there was moderate evidence to suggest that 'advance care planning led by skilled facilitators who engage key decision

⁵ This finding held true in further literature searches conducted for this thesis between 2010 and 2013.

makers and interventions' may reduce caregiver burden (pg. 147). The authors also reported that evidence aimed at reducing caregiver burden within a cancer population was weak (ibid).

2.6 Positive aspects of caring

As noted by other commentators, the 'burden' of care is widely reported, whilst the positive aspects of caring are often less widely reported (Hudson 2004).

Kramer (1997) identifies four reasons why it is important to explore positive aspects of caring. These are; caregivers want to talk about positive aspects of care, the benefits to clinicians, which is important to the advancement of quality of care and support, and the need to further theory in this area (Kramer 1997 reported in Cohen, Colantonio & Vernich 2002)

Nolan, Grant and Keady (1996) assert that 'satisfaction with caring' consists of three dimensions:

1. Satisfaction gained from interpersonal dynamics between carer and the cared for person
2. Satisfaction gained from intrapersonal orientation of the carer
3. Satisfaction gained from the desire for positive outcomes and avoid negative outcomes for the person they are caring for

(Adapted from Cohen, Colantonio & Vernich 2002, p. 184)

Cohen, Colantonio and Vernich (2002) conducted a large study on the positive aspects of caregiving in Canada. Of the 289 carers of older people questioned, 211 (73%) named at least one positive aspect of caring, and an additional 20 (7%) named two or more positive aspects of care.

In a study of 47 people providing home-based care to a friend or relative with advanced cancer, all participants identified challenging aspects of their role (Hudson 2004). This included their own health problems, perceived lack of skills to manage the patient's symptoms, a lack of support from health care professionals, family issues, the patient's deterioration and not having time for themselves. Sixty percent of carers were also able to identify positive aspects of their caregiving role. This included forming a closer relationship with the person they were caring for, learning about their own personal resilience in the face of adversity and taking on new challenges. This study is useful as it highlights both positive and negative aspects of the caregiving role. It is problematic however that Hudson does not present the positive findings thematically, as he does the negative findings. Rather, all positive quotes are presented in one table. The extent to which these positive aspects exist in relation to the negative is unclear, which may suggest that the negative aspects

outweighed the positive aspects that were reported. Furthermore, four caregivers could not identify any positive aspects of their role.

Gender specific studies have reported similar findings. Ribeiro and Paul (2008) interviewed 53 male carers in their study, of which, 32 reported positive aspects of care. In contrast to the Hudson (2004) and Cohen, Colantonio and Vernich (2002) papers reported above, this study did not specifically ask about positive aspects of caring. The authors found that older male caregivers reported 'satisfaction' and 'perceived social honour' as positive aspects of caring for their wives with dementia and physical disabilities (p. 169). Although it is interesting to report the findings of a male focused study, the study is of limited transferability to the present study as the research was undertaken in Portugal, which may have different cultural connotations with caregiving. Furthermore, the study was not specific to life-limiting illness.

2.7 Interactions between systems of formal and informal care: partnerships in family care?

The literature presented so far has addressed caregivers' needs, positive and negative aspects of caregiving, and the important role that family caregivers play in providing unpaid 'informal' care for their relative. In addition to this 'informal' care is the 'formal' care provided by health and social care professionals, such as a GP, community nurses, doctors, nurses and health assistants in hospital and 'formal' or 'paid' carers who provide health and social support at home. A fundamental part of the experience of family caregivers is the interactions with the person they are caring for, as well as other professionals, and non-professionals who they may encounter during the illness trajectory. However, there appears to be little research regarding the experiential nature of these dynamics, particularly in the area of palliative care. This section explores the existing body of literature in this area.

As identified in the previous chapter, recent policies in health, social, and end of life care have emphasised the important role of family caregivers. This change of rhetoric is mirrored in the research literature in this area. The term 'integrated care', for example, is often used to describe interactions between various aspects of health and social care, and is a term used throughout Europe (Leichsenring 2004). Integration between the various health and social care services is key to successful end of life care (NHS National End of Life Care Programme 2012).

Studies of health and social care integration are important as they help to identify elements of good practice and how to improve services. This study does not intend to unpick the interactions between these agencies, but views health and social care as being part of a 'formal system of care'; that is, care and support that is accessed through the welfare state in England.

Nolan (2001) identified four common models of caregiving interaction:

1. *Carer as a resource*: the rationale for interventions is to maintain carers in their role.
2. *Carers as co-workers*: greater attention is given to caregivers' individual needs, but maintaining the caregiving role is the primary motivation.
3. *Roles of carers being replaced*: services are devised to replace the carer, either in the interests of the carer or the cared for person.
4. *Carers as partners in care*: focus on empowering carers.

(adapted from Nolan 2001, p. 92)

Nolan argues that these existing models are inadequate for defining relationships between family carers and health and social care professionals (2001 p.92) and instead champions the 'carers as experts' approach (Nolan 2001; Nolan, Grant & Keady 1996), which he describes as:

- *The primary purpose of the carers-as-experts approach is to help carers to attain the necessary competencies, skills and resources to provide care of good quality without detriment to their own health. In this context, helping a carer not to take up or to give up care is a legitimate aim.*
- *It is essential to consider both a carer's willingness and ability to care. Some family members may not really want to care but may feel obliged to do so. Conversely, while many family members may be willing to care, they may lack the necessary skills and abilities.*
- *A comprehensive assessment will include not only the difficulties and demands of caring, but also the quality of past and present relationships, the satisfactions or rewards of caring and the range of coping and other resources, for example, income, housing and social support that carers can draw upon.*
- *The stresses or difficulties of caring are best understood from a subjective rather than an objective perspective, with the circumstances of care being less important than a carer's perception of them.*

(Nolan 2001, p. 94)

He explains:

'carers-as-experts' recognises the changing demands of care and that skills and expertise develop over time. A temporal dimension is therefore crucial, and this suggests varying degrees of 'partnership'. (Ibid)

Nolan asserts that these 'varying degrees of partnership' may occur for new caregivers, where the carer may be the 'junior' and health and social care professionals take on a 'senior' role (Nolan 2001, p. 95). Conversely, for more experienced caregivers who have a wealth of understanding of their relative's condition and needs, these positions may be reversed and that these balances are likely to shift throughout the illness trajectory (ibid).

A number of studies have examined the interactions between formal and informal care in the home (Ward-Griffin & McKeever 2000; Ward-Griffin, McWilliam & Oudshoorn 2012). One study described how relationships between family carers and community nurses developed over the period of illness and may occur in the following sequence:

- 1) *Nurse-helper relationships*: nurses provide and co-ordinate the majority of care, with family carers adopting a supportive role.
- 2) *Worker-worker*: co-worker relationship adopting a 'teamwork' approach, in which nurses recognise the expertise of family carers.
- 3) *Manager-worker*: nurses' visits may reduce as family carers take increasing responsibility for practical care. Nurses adopt a more advisory or managerial role.
- 4) *Nurse-patient*: nurse as nurse- family carer as patient. Family caregivers develop own support needs and or experiences issues relating to their own health and well-being.

(adapted from Ward-Griffin & McKeever 2000)

The authors noted that the nurse-helper relationship was the dominant relationship type in palliative care. Within this relationship there are clear power dynamics, with the nurse assuming the majority of responsibility of care. The worker-worker relationship was found to be fraught with difficulties between family carers and nurses. The authors attributed these difficulties to differing expectations between family carers and nurses regarding the level of responsibility of practical nursing tasks that family carers should take on, noting that 'family caregivers had a great deal of responsibility with little authority' (Ward-Griffin & McKeever 2000, p. not available). The nurse-patient relationship often resulted later in the illness trajectory, often as a result of family caregivers providing home based care for a prolonged period of time, pre-existing medical conditions, or where caregivers displayed signs of caregiver 'burden' (ibid).

The authors challenge the notion that a 'partnership' can exist between family carers and community nurses providing home based care, due to the lack of equality in these 'partnerships'. Furthermore, the authors assert that interactions between community nurses and family carers were often 'complex, dynamic, and multi-faceted' (Ward-Griffin & McKeever 2000, p. 89).

Ward-Griffin and McKeever's study was concerned with carers of their elderly, frail relatives, therefore there are likely to be both similarities and differences between the author's findings and those presented in this thesis. However, the authors assert that carers of people in the palliative phase felt more supported than those caring for a relative with a chronic illness.

The authors call for further research to be undertaken in this area in order to better understand these relationships. In the time since this research was conducted (2000) there has been little further research in this area.

In 2012, Ward-Griffin revisited the ideas presented in her earlier work (described above). The ethnographic study aimed to examine the relational experiences between patients, health and social care professionals and family caregivers providing home-based care to an older-adult with advanced cancer (Ward-Griffin, McWilliam & Oudshoorn 2012). The perspective of family caregivers were gathered via observations and in depth interviews with four family caregivers over a period of 6-8 months. The authors found that caregivers often hid their 'true feelings' about their caregiving role and presented both 'public' and a 'private' faces (p. 510). The authors argue for a more 'relational' approach to care in order for family caregivers to feel valued and supported in their role (p. 511).

The interactions between nursing home residents and staff have also been examined as a dyadic care relationship, from the perspective of nursing home staff (Oliver, Porock & Oliver 2006). This study draws on Goffman's 'dramaturgical' model of social interaction as a theoretical framework (Goffman 1959). The authors argue that in nursing homes, end of life issues are brought from 'back stage' to 'front stage'; issues regarding death and end of life care are addressed head on with family members and nursing home staff (Oliver, Porock & Oliver 2006). This article is of limited applicability as it addresses the relationship between nursing home staff and residents; interactions and relationships with family carers are not addressed in the study.

The interactions between formal systems of care, informal systems of care and the cared for person are important throughout the illness trajectory and not just at the end of life (Guo, Phillips & Reed 2010). The study explored bereaved family caregivers' perceptions about their interactions with healthcare professionals (excluding hospice staff). The study is based

on twenty-seven interviews with caregivers of older people at the end of life. Their findings highlight positive and negative interactions between caregivers and health and social care professionals. Figure 6 provides a summary of the authors' key findings.

The findings presented in Guo, Philips and Reed's study are rather simple and lack the detail that gives the reader an insight into the complex interactions in healthcare relationships. It should be asserted however that the authors do state that this article reports the findings of a larger study. The findings presented in this thesis aim to contribute to what is known about this issue.

Good interactions	Bad interactions
Caring and friendly	Insensitivity
Taking the time to listen	to patient's pain
Being supportive	to patient's privacy
Trust in caregivers' competences	to patient's physical conditions and needs
	to caregivers' feelings
	shown when there were conflicts between needs of patients
	and needs of the hospital
	shown by ignoring the patient's symptoms and delaying
	treatment
	Noncommunicative
	inaccessibility: availability and time
	content
	protection
	Untrustworthy
	treatment care plans
	safety
	Giving up too soon
	Power struggles

Figure 6: Major categories of good and bad interactions (Guo, Phillips & Reed 2010, pp. 336, reprinted with permission)

Examining the relationships between patients, family cares and health and social care has been a topic of academic interest for over two decades. Research in the early 1990's explored both dyadic and triadic relations:

Caregiving is part of a process of change in time, and dyadic interactions are likely to be affected by the course of the illness and the upward or downward trajectory of the patient, as well as the reactions and the changing life circumstances of the caregiver. (Kahana and Young, 1990, cited in Nolan et al. 2003, p. 4)

Nolan further summarises Kahana and Young's ideas, highlighting the authors' assertion that future research in family caregiving should focus on triadic interactions between patients,

family carers and health and social care professionals, as 'a better understanding of the needs of cares would only emerge if greater attention was paid to the way caregiving partnerships change over time'. (Nolan et al. 2003, p. 5).

Rolland (1988, 1994) proposed a further model of care, which he called the 'therapeutic quadrangle', which incorporates the perceptions of the cared for person, family caregiver(s) and health and social care professionals alongside the nature of a person's illness (Nolan et al. 2003). Recognising the person's illness within this model adds an important dimension, as the nature of the illness provides context for the likely progression of the illness and therefore highlights how care may change over time (p. 5).

2.8 Priority areas for future research in supportive and palliative care

It is important to address priority areas for research in supportive and palliative care and to make a contribution to knowledge in these areas. A recent assessment of research priorities (as perceived by members of The International Palliative Care Family Carer Research Collaboration and others who had expressed an interest in this group) identified intervention and bereavement research as key priority areas (Hudson, Zordan & Trauer 2011). The full list of priority areas is provided in Table 6. These priority areas support those reported by Grande et al. (2009), who also identified research into supportive interventions for this population as a key priority for future research.

The experience of family carers was identified as a key priority area for research (see Table 6). This thesis aims to make a useful contribution to this priority area. This thesis also attends to issues relating to the role of family carers, communication and touches on the area of family dynamics.

Finally, Hudson and Payne (2011) assert that, in order to adequately support both patients and their families within palliative care there needs to be:

'Substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils' (p.867).

With this in mind, the findings of this study will be discussed with reference to research, policy and clinical practice in Chapter 11.

Table 6: Priority areas for family caregiver research (Hudson, Zordan & Trauer 2011, p. 399).
Reprinted with permission.

Priority area	Number of statements
Interventions	28
<i>Timing & dose of interventions</i>	10
<i>Self-care</i>	4
<i>Promotion of consumer empowerment/advocacy</i>	4
<i>Therapies</i>	4
<i>Promotion of the positive/enhance satisfaction</i>	4
<i>Use of technology</i>	1
<i>Economic value</i>	1
Bereavement	17
<i>General</i>	8
<i>Prevention / anticipatory grief</i>	5
<i>Post-death</i>	4
Under researched groups e.g., younger/older/children/teenagers/male carers	10
Psychosocial assessment and support	10
Needs assessment	10
Site of care	8
→ Experience of the family carers	8
Services—accessibility	6
Culturally and Linguistically Diverse (CALD) groups	5
→ Family dynamics	5
AIDS*/dementia/comorbidities e.g. cancer and dementia	5
→ Role of the family carer	3
Respite	3
Advance Care Planning	3
Family meetings	2
→ Communication—health professionals/family	2
Health professional training	2
Financial impact	2
Policy	2
Quality of life	1
Theoretical frameworks and definitions	1
Spiritual	1

*AIDS, acquired immune deficiency syndrome.

Chapter 3

Methodology

3.1 Introduction

This chapter outlines the methodological approach taken in this study, including the philosophical underpinning and epistemology of the study, ethical considerations, and issues regarding the criteria for assessing quality in qualitative research.

Clough and Nutbrown (2002) assert the importance of adopting a research stance that is appropriate to the topic being studied (Clough and Nutbrown 2002, in Grix 2004). A qualitative approach was taken in this study, as this approach is sensitive to understanding the meanings attributed to situations by social actors. A quantitative approach was deemed unsuitable to investigate the research question posed by this study, as a quantitative approach would seek to prove or disprove a hypothesis or look for causal relationships, for example, rather than seeking to explore an issue or phenomenon, as is intended in this study.

Holloway and Todres (2005) assert that some qualitative research fails to address methodological issues in adequate detail. In order to ensure that methodological issues are adequately addressed in this thesis, epistemology, methodology and methods are made transparent.

It is useful to define key terms that will be used in this chapter. Crotty (1998) offers the following definitions of key terms:

- **Methods:** the techniques or procedures used to gather and analyse data related to some research question or hypothesis.
- **Methodology:** the strategy, plan of action, process or design lying behind the choice of and use of particular methods and linking the choice and use of methods to the desired outcomes.
- **Theoretical perspectives:** the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria.
- **Epistemology:** the theory of knowledge embedded in the theoretical perspective and thereby in the methodology.

(Crotty 1998, p. 3)

Crotty's explanations are useful, as he not only defines key philosophical/research terms, but attempts to demonstrate how they are interlinked. Carter and Little (2007) also emphasise

this interlinking, asserting that that ‘epistemology modifies methodology and justifies the knowledge produced’ (p. 1317).

Figure 7 provides a visual representation of the interlinked methodology adopted in this thesis (adapted from Crotty 1998, pp. 4-6). This diagram follows Crotty’s ideas of a framework in which ontology and epistemology are presented alongside one another to inform the theoretical perspective (ibid). The presentation of this chapter also follows this structure.

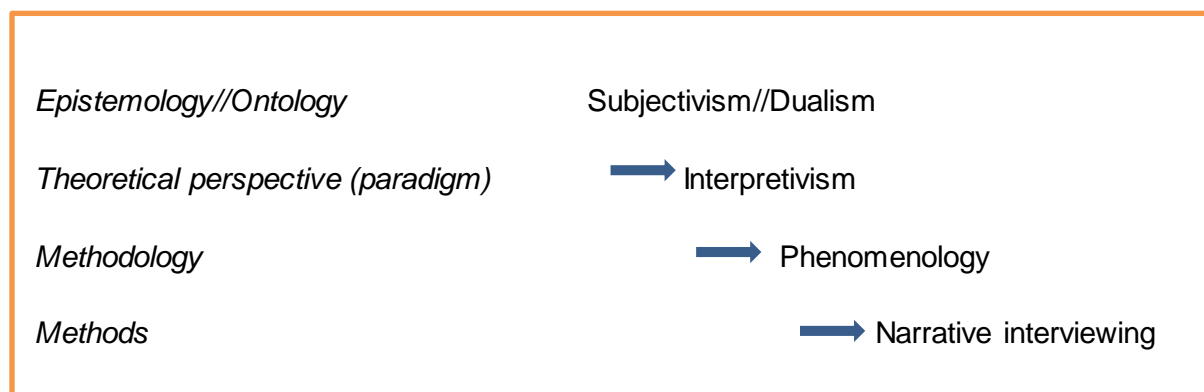


Figure 7: methodological perspective

3.2 Ontology and epistemology

Establishing a clear epistemological position is important, as this forms the foundations on which the research aims are investigated through the associated research design, analysis and interpretation of findings (Oliver 2008). However, it should be recognised that there is some contradiction in philosophical literature about what constitutes as an epistemology, often with little explanation of the term’s categorisation. For example, Crotty (1998) describes constructionism as an epistemology and interpretivism as a theoretical perspective, whereas Bryman (2008) describes constructionism is an ontological position, and interpretivism an epistemology. There is little recognition of such contradictions, nor discussions or debates to help clarify or justify the opposing stances. Crotty (1998) asserts that many texts describe epistemologies and theoretical perspectives as being interchangeable and make little attempt to classify or distinguish between them. His text attempts to clearly outline different aspects of social theory and position them in relation to one another.

The epistemology of objectivism proposes that for something to exist it must be possible to be objectively measured and evaluated. Objectivism is closely aligned with positivism and the research principles of the natural sciences. This epistemology underpins the principles of quantitative research in the social sciences (Crotty 1998). By contrast, the epistemology of

subjectivism holds that something can exist that cannot be easily seen, touched or measured. Concepts such as 'culture' or 'community' are useful examples of things that exist, but cannot be touched or easily measured; indeed, these concepts may be interpreted and understood differently by different people. The research presented in this thesis derives from a subjectivist epistemology.

Willis (2007) defines ontology as being 'concerned with the nature of reality (or being or existence and that various ontological positions reflect different prescriptions of what can be real and what cannot' (p. 9). Major ontological positions include materialism, idealism, metaphysical subjectivism, and dualism.

- Materialism- only things that are physically tangible or material are real.
- Idealism- reality exists through mental and spiritual modes (Craig, 1998 in Willis 2007)
- Metaphysical subjectivism- human senses (sight, sound, touch, taste and smell) enable something to be determined as being 'real' or not.
- Dualism- originating from Descartes' notion that 'reality' has both physical and mental entities.

(adapted from Willis 2007, pp. 9-10)

A dualistic ontology is adopted in this study, stipulating that the nature of reality is both mental and physical. The ideas presented in this thesis derive from this understanding of reality.

3.3 The interpretivist theoretical perspective

This study draws on interpretivism as a theoretical perspective (also commonly referred to as the interpretivist paradigm). A theoretical perspective or paradigm may be more usefully understood as a *worldview* (Willis 2007).

The foundations of interpretivism can be traced back to rationalism, 'the idea that you can come to know reality by thinking about it' (Willis 2007, p. 49) and the writings of Plato, who emphasised the importance of thinking and reflection in the interpretation of physical objects (Willis 2007). Despite these early ideas, the dominant philosophy of the 18th-20th centuries was that of realism, which is aligned with scientific methods and the natural sciences (Willis 2007).

Interpretivism developed as a response to objectivism and 'scientific' approaches to social science (Willis 2007) and offers an alternative way of 'seeing' the (social) world to that of positivism and the natural sciences. Interpretivists believe that the social world, unlike the

natural world, cannot be measured in a scientific (positivistic) manner, as humans are social beings who interpret the world around them. This world is one where meanings are interpreted and understood by others. A diverse range of research methods, aligned with the philosophy of the interpretivism, have been developed to facilitate our understanding of the social world (Willis 2007).

Immanuel Kant proposed that, rather than understanding empiricism (reason leads to the truth) and rationalism (observation and experimentation leads to truth) as opposing viewpoints, that one cannot exist without the other and therefore should be viewed as a synthesis (Smith 2003, p. 133). Smith provides a useful summary of Kant's ideas, noting that 'without reason we cannot make sense of our experiences and without observation we have nothing to employ our capacity for rational thought' (p133).

Wilhelm Dilthey (1833-1911), an early social scientist and theorist, was amongst the first to give importance to recognise the significance of the social world and the 'lived' experiences of people. Dilthey argued that historical events should be understood within appropriate social and cultural contexts (Appelrouth & Edles 2012), or as Smith (2003) comments, Dilthey understood that 'while human beings acted *upon* the natural environment, they also acted *within* the social environment' (p. 161). Dilthey proposed the idea of the hermeneutic circle; 'the whole of a work must be understood from individual words and their combination but full understanding of an individual part presupposes understanding of the whole' (Dilthey 1896 in Smith 2003, p. 161). Smith offers a useful metaphor to aid our understanding of Dilthey's ideas. He explains 'a common metaphor for explaining this idea is the sentence analogue, whereby the meaning of a word is identified by reference to its place in a sentence and the meaning of the sentence is established through the meaning of the individual words' (Smith 2003, p. 161). Context is therefore central to interpretive research, as it provides a framework for interpretation and understanding. The hermeneutic circle is explored in greater detail later in the chapter.

Dilthey further contributed to early understandings of interpretivism by arguing that there are two types of knowledge; explanation and understanding, which are respectively aligned to the natural sciences and the social or human sciences (Harrington, 2000 in Willis 2007, p. 100). Central to Dilthey's emphasis on understanding (or '*verstehen*' in his native language of German) was that research into the lived experience was a worthwhile and 'legitimate' focus for research (Willis 2007, p. 100).

Sociologist Max Weber was significantly influenced by Dilthey's ideas and wrote extensively about *verstehen*, or *interpretive understanding* (Appelrouth & Edles 2012, p. 820). Weber's *verstehen* may be characterised as 'reflective reconstruction and interpretation of the actions

of others' (Holloway & Wheeler 2010, p. 25). Weber drew upon the following example to demonstrate his ideas on interpretive understanding: if one imagines an onlooker observing a woodcutter chopping wood, the onlooker must interpret the situation that is being observed in order to gain an understanding of the purpose of the action (Weber 1925 cited in Roth & Wittich 1978, p. 8). Our observations tell us that the woodcutter is performing the action of chopping wood, which he refers to as *direct observational understanding*. However Weber prompts us to think about how to interpret this action, which he refers to as *explanatory understanding*. The simple of action of the woodcutter chopping the wood does not explain *why* he is doing so: it is for fire to keep warm or for cooking, for exercise, because the tree is diseased, or is he cutting the wood to sell to others? This simple example is extremely effective in illustrating the importance of understanding context and the meaning behind actions that are central to interpretivism. The interpretivist paradigm, on which much qualitative research is based, therefore offers a meaningful way of viewing and researching the social world.

Finally, it is useful to tie the concepts and ideas discussed in this section together with the purpose of interpretivist research, as this demonstrates how the philosophical background is directly relevant to the research that is conducted within this theoretical perspective. The goal of interpretivist research, according to Willis, is to achieve 'an understanding of a particular situation or context much more than the discovery of universal laws or rules' (Willis 2007, p. 99).

This section has provided a summary of the historical and philosophical background of the interpretivist paradigm and the purpose of interpretivist research. The following section focuses on phenomenology, a methodology aligned with interpretivism, and explains why phenomenology was adopted as a methodological approach in this thesis.

3.4 Phenomenology

Phenomenology is part of the interpretive paradigm. Willis offers a useful explanation of phenomenology's interpretivist roots.

'Phenomenology is the study of people's perception of the world (as opposed to trying to learn what "really is" in the world). The focus is thus on understanding from the perspective of the person or persons being studied'. (Willis 2007, p. 107)

Developed in the early twentieth century by philosopher Edmund Husserl, phenomenology seeks to explore people's lived experiences and the meanings attributed to experiences by individuals, in order to gain an insight into the social world and understand the nature of a

phenomenon. The approach is principally concerned with people's subjective experience and the meaning of a phenomenon to an individual or group of people (Crotty 1998). It is based on the understanding that 'reality' is multiple, and socially constructed through the interaction of individuals who use symbols to interpret each other and assign meaning to perceptions and experience' (Bowling 2009, p. 139).

Phenomenology seeks to unravel the taken for granted common sense norms and assumptions of everyday life. This is a particularly useful theoretical position from which to examine the lives of carers of a person with a life limiting illness, as the everyday is re-examined by the participant and researcher.

Holloway and Wheeler (2010, p. 213) describe that there are three distinct branches of phenomenology: *descriptive* phenomenology, *interpretive* phenomenology and *existentialist* phenomenology. Descriptive phenomenology is aligned with the thoughts and theories of Edmund Husserl, whilst interpretive phenomenology is associated with Martin Heidegger. Existentialist phenomenology is acquainted with Merleau-Ponty and Jean-Paul Sartre.

It is useful to provide a brief historical background of phenomenology in order to understand the development of these two approaches (see Spiegelberg 1994 for a more detailed historical account). The German philosopher, Edmund Husserl (1859-1938) is often described as the founding father of contemporary phenomenology (Rapport 2005; Smith 2003). Husserl's descriptive phenomenology aims to uncover the 'lifeworld' (*lebenswelt*); the everyday, taken for granted, ordinary nuances of everyday life (Holloway & Wheeler 2010, p. 216).

Husserl believed that researchers should attempt to acknowledge and suspend their preconceived ideas about a phenomenon; a process which he refers to as 'bracketing' (Holloway & Wheeler 2010, p. 216). These preconceived ideas may be based on previous experiences, for example. By identifying one's preconceptions about a phenomenon, Husserl believed that bracketing could help to reduce bias in research and enable the researcher to impartially investigate the phenomenon under study.

Deriving from the traditional 'descriptive' phenomenology of Edmund Husserl is Martin Heidegger's 'hermeneutic' or 'interpretive' phenomenology. Heidegger (1890-1976) was Husserl's student and developed Husserl's ideas to go beyond simple description to the interpretation of meaning in language (Holloway & Wheeler 2010, p. 217).

Contending Husserl's notion of 'bracketing' existing knowledge, Heidegger argues that it is neither possible nor favourable for a researcher to put aside his/her opinions. Rather,

Heidegger argues that the researcher is an integral part of the research process and as such should acknowledge and examine his or her prior assumptions (Holloway & Wheeler 2010).

Rapport (2005) provides a useful example of the objectives of a Heideggerian phenomenological researcher:

“Researchers following a Heideggerian tradition emphasize the interpretive approach to understanding phenomena. They attempt to develop notions of the way human beings give meaning to experience, behaviours and action, while making sense of the world through understanding and the clarification of speech and language”. (Rapport 2005, p. 127)

Hermeneutic phenomenology is widely used in the social sciences to research topics that require an understanding of a particular social phenomenon and has been usefully applied to nursing and other health and social care research (Holloway & Wheeler 2010; Leonard 1994; Rapport 2005). Likewise, the approach is useful to this study, as this study seeks to understand the experiences of family caregivers.

Following the ideas of the German philosophers Husserl and Heidegger, French Jean-Paul Sartre and Merleau-Ponty referred to their ideas not as phenomenology, but as existentialism (Holloway & Wheeler 2010). Holloway and Wheeler note that for Sartre, ‘research would focus on real and concrete thoughts and behaviour before imaginary or idealised qualities or essences’ (p218).

Having examined the philosophical and theoretical roots of phenomenology, this section now turns to address how these theoretical aspects translate into research practice. Holloway and Todres (2005) offer the following breakdown of the dimensions of descriptive phenomenological research:

- Goal:* [To] describe, interpret and understand the meanings of experiences at both a general and unique level.
- Research question:* What is the structure of this particular experience? What is it like to be or experience a particular situation?
- Data gathering:* Focused on the depth of a particular experience; interviews, narratives- anything that is able to describe the qualities of experiences that were lived through.
- Analysis:* Thematic analysis which clarifies the meanings by moving back and forth between whole meanings and part meanings.

Presentation of results: Different levels depending on audience and purpose: a description of the essence (structure) of the experience, its 'bare bones'; followed by how each theme occurs in different and unique ways.

Knowledge claim: Transferable general qualities (essences) of what makes the experience what it is; description of unique contexts. Empathic understanding.

(adapted from Holloway & Todres 2005, pp. 94-95)

The following extract offers a further summary of how the theoretical aspects of phenomenological research may be put into research practice:

Phenomenological research focuses on the lifeworld, lived experiences which are described by the participants who reflect on them. These experiences might include 'the experience of diabetes', 'being a first-time mother', 'living with epilepsy', and similar phenomena. From these experiences phenomenologists gain insight and extract common themes- essential structures or essences- which human beings have in common and that go beyond individual cases (Todres and Holloway, 2006). Thus, a phenomenological study presents the essential structure of a phenomenon'.

(Holloway & Wheeler 2010, p. 220)

In summary, phenomenological research seeks to understand people's 'lived experiences' and seeks to uncover the 'essence' of such experiences by identifying common themes that are shared by the population under study (Todres and Holloway 2006 cited in Holloway & Wheeler 2010, p. 221). The 'essence' of the experience of being a family caregiver will be illuminated in this thesis through a thematic presentation of results in chapters 6-10.

Reflexivity is an important component of phenomenological research practice. Holloway goes so far as to say 'reflexive writing and aesthetic presentation is an essential and integral element in phenomenological research' (Holloway & Wheeler 2010, p. 221). Researchers in this tradition acknowledge that they bring with them their own set of assumptions, beliefs and way of seeing and interpreting the social world and therefore accept that they are part of the research process and the knowledge produced (Holloway & Wheeler 2010).

In keeping with the view that the researcher is an integral part of the research process, rather than a neutral observer, phenomenological researchers accept that their research cannot be easily duplicated due to the context in which the research was originally conducted. Holloway and Wheeler (2010) note that this includes 'the research relationship, history and location of

participants' (p. 26). The authors also summarise Gadamer's (1975) interpretation of Heidegger's ideas, noting that 'preconceptions and provisional knowledge are always revised in the light of experience and reflection. The text is always open to multiple interpretations because researchers or reflective persons are involved in their own relationships with the world and others' (Holloway and Wheeler 2010 p. 220).

The research presented in this thesis adopts the interpretive phenomenological stance of Heidegger, as the research seeks to 'interpret the meaning of the phenomenon in context' (Holloway and Wheeler 2010 p. 228). In keeping with the hermeneutic approach, the process of 'bracketing' was rejected, on the grounds that one's prior understanding cannot be separated from the process of analysis, and add to the researcher's interpretation of the data.

3.5 Other approaches considered

Narrative and grounded theory approaches were also considered for use in this study. This section briefly discusses these approaches and provides an explanation as to why the approach was rejected.

3.5.1 Narrative

Narrative research seeks to understand a phenomenon through the detailed description of an event, as experienced by a participant. Essentially it is the storied telling of an event, experience or aspect of life by a participant. In health research it is commonly used to gain insight into patients' experiences of illness, particularly chronic illness (see Bury 2001; Frank 2010). Narrative methodology in palliative care research has also gained popularity in recent years (see Rolls, Payne & Brown 2009).

Narrative research also holds significant clinical utility (significance to clinical practice). For example, in a collection of narratives of palliative care experiences of patients and their families in North America, Barnard et al. (2000) assert that their work does not seek to provide guidance on good practice in palliative care, but rather tell the stories of *real* patient and family experiences. They hope that their work 'helps us to compare palliative care ideals with narratives that portray the actual practice of the discipline' and that the aim of their work is to 'elicit empathy, understanding and discussion' (Barnard et al. 2000, p. 2).

Narrative methodology was rejected as a methodological approach in this study as it is not generally appropriate for use in studies where a large number of interviews have been conducted, due to the level of detail required in analysis (Riessman 2002).

3.5.2 Grounded Theory

Grounded theory was initially considered as a theoretical approach to the study and as a method of data analysis.

Glaser and Strauss' grounded theory was first developed and used in the field of health research to research the experience of dying patients in hospital (Glaser & Strauss 1965). It has since gained popularity in qualitative research in the social sciences, and particularly in the field of health research.

The key objective of grounded theory is to generate a theory which is borne out of the data (Glaser and Strauss 1967; Strauss 1987; Glaser 1998; Strauss and Corbin 1998, all in Bluff 2005). Grounded theory is often used to research areas where little is known about a phenomenon (Stanley 2006), there is a lack of theory in the area under study (Glaser and Strauss 1967; Schreiber and Stern 2001 in Bluff 2005), if current theories fail to adequately explain a problem (Chenitz and Swanson 1986, in Bluff 2005) or to develop an existing theory (Bluff 2005).

The philosophy and principles of grounded theory were appealing; I found the structured approach, as described above, particularly appealing and was drawn towards a method which has clear guidelines on data analysis and is less flexible than other methods of qualitative analysis. Furthermore, my background in sociology, and particular theoretical interest in symbolic interactionism, drew me towards grounded theory as the philosophical roots of grounded theory are embedded within this approach.

Grounded theory was rejected as a methodological approach in this study on the following grounds:

- a preliminary literature review had already been completed to inform the project and an interview schedule devised based on existing literature. As noted above, there is some debate in grounded theory literature about the extent of and timing of a literature review. However, as this literature review was only preliminary, it would be considered acceptable by the Straussian school of grounded theory.
- Many interviews were carried out in a short space of time, following a very successful advertisement in a local newspaper advertising for study participants. This meant that it was not possible to follow the constant comparative method of data analysis that is essential to grounded theory.
- Grounded theory is most useful in studies where little is known about the phenomenon under study. In contrast, much research has been conducted on the broad topic of carers

and patient experiences. This study seeks to look at specific aspects of the caring experience in more detail.

3.6 Summary

This chapter establishes the researcher's ontological and epistemological positions, theoretical perspective, and the methodology that underpins the research presented in this thesis (see Figure 7). Clear links have been made between these positions, demonstrating how the positions are aligned. The chapter has discussed the historical and philosophical underpinnings of interpretivism and phenomenology. The foundations of the interpretivist paradigm have been explored and links made with the purpose of interpretive research to the present study. The chapter has demonstrated the suitability of the approaches adopted in this research study and has identified that interpretive phenomenology is adopted in this study. The chapter has also provided justification for the rejection of other approaches.

Leading on from this, the following chapter presents the research methods that were adopted in this study.

Chapter 4

Methods

4.1 Introduction

This chapter discusses issues regarding the selection and application of the methods employed in this study. Issues such as the research population, the recruitment of participants and approaches to interviewing are addressed. Considerations of data analysis are also discussed in detail. Finally, issues regarding the quality of the research and ethics are considered.

The methods discussed in this chapter are aligned with the interpretivist paradigm, as discussed in the previous chapter.

4.2 Issues for consideration in retrospective research

Issues regarding memory and the accurate recall of events are relevant to the retrospective nature of this study. Psychology offers valuable insights into the accuracy of recall over time and this issue has been addressed in several research studies in end of life care. For example, Addington-Hall and McPherson (2001) addressed the effects of bereavement on memory in evaluating the validity of retrospective accounts. Research in cognitive psychology describes how negative emotional states, such as anxiety and depression can result in negative recollections attributed to that time period. The implication of this to post-bereavement interviews is that negative states of mind are likely to elicit negative recollections. On this basis it would seem plausible to interview bereaved family members or carers some time after their bereavement, when their emotional state may be improved.

Research in cognitive psychology suggests that time is an important factor in recalling accurate information (Baddley in Addington-Hall & McPherson 2001). The accuracy and ease of recollection of events changes over time, as rather than memories decaying over time, new information makes older memories more difficult to access (ibid). It is therefore preferable to ask people to recall events as soon as is ethically possible (Addington-Hall & McPherson 2001). However, research drawing on narrative inquiry recognises that the research is a “collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus” (Clandinin & Connelly 2000), which indicates that additional factors contribute to the telling and interpretation of a person’s narrative.

The time reference period for interviews in the present study was a minimum of six weeks post bereavement, and a maximum of five years. This time period was carefully considered

and was based on evidence from prior research and ethical considerations. The following caption provides an insight into the researcher's observations on post-bereavement interviewing. The content is adapted from a research diary that was kept for the duration of the study.

Researcher reflections on post-bereavement interviewing:

A number of interviews took place shortly after bereavement (6 weeks-6 months). I found that interviews that were conducted some time (1+ year) after death were often more reflective and considered accounts. I noted that, as well as being able to recall detail about their experiences, these participants were able to see the 'bigger picture' in terms of their caring experience and often offered evaluative and constructive comments. Such participants were able to put themselves into the picture to a greater degree than participants who were more recently bereaved, giving rich insights into the experience of caring for a family member with a life limiting illness. I believe that having a range of time since death was beneficial to the study, as it provided richness and differing perspectives.

Little research has been conducted examining the impact of the timing of the interview to the perception of quality of end of life care (Teno 2005, p. 46). Teno (2005) asserts that although numerous studies have been conducted on the agreement between recall and time reference periods in measuring pain and symptoms, that there is a dearth of studies that attempt to assess whether proxies' assessment of quality of care for both the patient and the carer changes over the period of bereavement (ibid). This gap in the literature is yet to be fulfilled.

The issues raised above were carefully considered in relation to the early design stage of the present research study. Further consideration was also given to these issues during the analysis stage. The relevance of these issues to the study were considered in relation to the study's interpretivist theoretical perspective, which recognises that experiences are interpreted events. In this study, the narratives are storied accounts of interpreted events. Furthermore, these stories are then interpreted by the researcher during data analysis and presented as research findings. This study is primarily concerned with experience (subjective understanding) rather than objectively evaluating a particular end of life service (such as the VOICES questionnaire (Addington-Hall et al. 2011)).

Furthermore, Teno (2005) asserts that the World health Organisation (WHO) identifies the family as part of the unit of care in its definition of palliative care. She argues that It is

therefore important to recognise families' views of care in their own right and not just as a proxy for their deceased relative, as these perceptions serve as 'important indicators of the quality of care' (2005 p47). This perspective is adopted in present study, which aims to investigate carers' experiences in their own right.

Much of the literature in this area focuses on the comparison of quantitative assessments of issues such as pain and symptom management and quality of life. The present study seeks to understand the experiences of family caregivers through retrospective qualitative interviews. Although issues such as quality of care and access to services will inevitably be explored in interviews, such issues are inherently different from quantitative comparisons or ratings of pain, for example. Rather, the focus is on the subjective understanding and meaning of events and this period of life to the bereaved carer. It is this subjective understanding of events that remain with carers throughout their life, well after their loved one has passed away (Saunders cited in Department of Health 2008b), and is therefore an important area for end of life and palliative care research.

4.3 Ethical considerations

Ethical issues were carefully considered at the design stage of the study and were revisited throughout the research process. This section outlines these considerations.

Ethical approval was obtained by the University of Liverpool Local Research Ethics Committee (UoL LREC) under the reference RETH000268⁶. Ethical approval was also gained from various charities that publicised the study. In these cases, documentation for the study such as the participant information leaflet, consent form, UoL LREC approval, plus any other documents requested to the appropriate person at the charity and awaited their feedback. The study was approved in all cases, often with encouraging feedback that this was a worthwhile study. Anonymity, confidentiality, informed consent and the right to withdraw at any time were all adhered to.

The inclusion criteria for the study stipulated that interviews would be carried out a minimum of six weeks after the death of the patient. The researcher acknowledges that bereavement and grieving is different for everybody, however six weeks is arguably a reasonable amount of time to set as a minimum participation period to allow for grieving, reflection and also to minimise the risk of the participant being 'vulnerable'⁷ when consenting to take part in the research study. In practice the minimum amount of time between bereavement and the interview taking place was around three months, with the majority of participants being towards the latter end of these criteria.

⁶ See Appendix 1.

⁷ See the Safeguarding Vulnerable Groups Act 2006 (The National Archives 2013) for further details.

Informed consent was sought from all research participants⁸. Potential participants were given a participant information sheet by the researcher, or were sent an information sheet in the post or by email depending on preference and method of recruitment⁹. All potential participants were advised that the researcher would contact them the following week, in order to allow adequate time to receive the leaflet and to read and reflect on the information before coming to a decision. If the participant was happy to take part in the study, an appointment was made for interview. Participants were also offered a further opportunity to discuss any aspect of the study or participation face to face with the researcher when the researcher arrived for the interview. Two copies of the consent form were also signed by both the participant and the researcher; one for the participant to keep and one for the researcher's records.

Confidentiality was a central concern in the ethical considerations of this study. All participants were informed of the measures taken to ensure their anonymity; pseudonyms were given to participants, other people and places. Participants were also advised that the small extracts from transcripts would be used in the final thesis and subsequent publications.

Particular ethical consideration was given to the discussion of sensitive topics. Questions were always asked in a sensitive manner and responses dealt with empathetically. As part of the distress protocol participants were offered a break if they became upset during the interview¹⁰, although this offer was not always taken. On one occasion the researcher insisted on a break as the participant was getting rather distressed; *'I think it would be a good idea if we took a short break'*, to the participant's agreement. Often the participant would go to the bathroom or make a cup of tea during a break. Some participants apologised for getting upset and began to talk informally. Often this was very insightful and was sometimes captured on the audio recorder, depending on the circumstances. If we had moved from the living room to the kitchen for example, I may ask the participant to repeat what they had said during the break when the tape recorder was back on, although this was not always possible, nor always appropriate.

It is worth noting that the occasions where participants became upset were almost always during a prolonged narrative. To the researcher's recollection, and in consultation with field notes, none of the participants in the study became upset as a direct response to a question.

Where appropriate, participants were advised to visit their GP if they were struggling with their grief. A number of participants commented that they had not thought that they needed it

⁸ See Appendix 3.

⁹ See Appendix 2.

¹⁰ See Appendix 5.

in the initial bereavement period (being 'strong' and 'getting on with things'), but may now consider it.

Although many participants became upset at times during the interview, nearly all participants commented that they had found being interviewed a positive and in many cases 'therapeutic' experience. A number of participants commented that the support offered from family and friends often disappeared after the initial bereavement period and that this was the first time they had had the opportunity to talk about the experience in detail with someone for some time. Some participants explained how they had valued the opportunity to take part in this research, as they were able to revisit feelings and reflect on their experience without 'burdening' their family and friends. For example, Claire described how friends and family often asked '*how are you?*', but explained that, after a while, this becomes a pleasantry rather than 'really' wanting to know. She felt that she could not 'burden' her friends and family any longer with her grief, so kept it to herself, putting a 'happy face' on to the outside world to disguise how she felt inside. Another participant, Pauline, commented that she greatly valued the opportunity to spend time reflecting on her experiences in this way.

A sensitive approach was taken to recruitment for this study. For example, posters were not displayed in hospices and in some charities that dealt with end of life support, as it may be considered inappropriate to display posters looking to recruit bereaved family carers when a person may be very ill. Rather, posters were displayed in public places and a notice put in a small number of charity newsletters, with a large and diverse readership.

There are also ethical considerations regarding researchers' wellbeing. For example, Gilbert (2002) warns of the emotional challenges such as 'burnout'¹¹ for researchers working with bereavement stories. In 2011 a peer support group for researchers working with emotionally challenging topics was introduced within the Institute of Psychology Health and Society at the University of Liverpool. Sessions were facilitated by a clinical psychologist and attended by both PhD students and research staff in the institute. These sessions offered a confidential and supportive environment for members to discuss a range of issues, including challenging emotional issues arising from the research studies they are involved in. Gilbert (2001) also warns that researchers may construct a 'self-protective shield to protect against emotional overload' (in Gilbert 2002, p. 235). The researcher hoped that participation in the support groups would help to guard against this and also lead to a fair and unbiased representation of narratives (Gilbert 2001 in Gilbert 2002). Support was also gained from fellow student peers in the department as well as the researcher's supervisors.

¹¹ A 'physical or mental collapse caused by overwork or stress' (Oxford Dictionaries 2013)

4.4 Subjectivity and reflexivity

Qualitative research entails a greater degree of subjectivity and interpretation than quantitative research. From the choice of research question to methodologies, analysis and interpretation, many subjective decisions are made by a researcher or team of researchers (Elliot 2006).

Reflexivity is a valuable practice for qualitative researchers; engaging in critical reflection aids in providing transparency in decision making, logging thoughts, developments and decisions made throughout the research process (Holloway 2005; Holloway & Wheeler 2010).

Throughout the thesis I present a personal reflexive voice in italicised text to distinguish the primary voice of the thesis and the reflexive voice of the researcher (Edwards 2005, p. 53). As a novice qualitative researcher I found this a particularly useful approach, as it enabled me to acknowledge my own reflections and development as a qualitative researcher, whilst maintaining a professional (third person) style throughout the main body of text. I hope that sections in italicised text provide the reader with a useful insight into the practice of reflexivity throughout this study.

Keeping a research diary can encourage 'ongoing reflexivity- [and a] critical self-awareness' of the research process (Riessman 2008, p. 191). Reflexivity was an early consideration in the research process and one that I actively engaged with throughout the study. I felt that keeping a research diary was a useful way of logging thoughts and decisions on research practices, as well as personal reflections on various aspects of the research process.

Field notes also offered a further outlet for reflections on each research interview, including notes on the participant or participant's narrative, as well as personal reflections on the interview and interview style.

As discussed earlier, qualitative research is a subjective process. It is good practice therefore for researchers to be self-aware of and make explicit their possible preconceptions and assumptions in order to acknowledge and understand the possible impact this may have on the research (Holloway & Wheeler 2010, p. 9). Some personal reflections are offered below:

As noted earlier, my initial personal motivations to study this topic and interest in palliative care research evolved through taking part in an overseas charity trek for a local hospice. Many of the sixty people who took part in this trek were bereaved family members of people who had been cared for in the hospice and several hospice staff took part in the trek. I got to know many other participants in the year leading up to the trek, through various meetings and training excursions, as well as through the unmistakable bonds you form with people on

what was, for many, a physically and emotionally exhausting time. As a group we got to know one another and we learnt about one another's stories and personal experiences. I also found out more about the important work that the hospice staff do in caring for and supporting patients and their families, from the perspective of both relatives and staff members.

I embarked on this study as an early career female researcher, aged 26-30 during the undertaking of this study. Whilst I have not had first-hand experience of being a family member's main caregiver, I witnessed my parents caring and supporting their parents (my grandparents) as they became increasingly frail and elderly. My grandmother sadly passed away in January 2011, aged 90, after a long hospital stay due to pneumonia. This experience gave me an insight into the varied practical and emotional complexities of caring for a family member at the end of life. This difficult personal experience may have contributed to my interpretation of the narratives told in this study.

The chapter so far has provided a general background to the methods employed in this study. The remainder of the chapter attends to practical aspects of the research process.

4.5 Research population

The inclusion criteria for the research study were:

- Age 18 and above¹². No upper age limit
- Both males and females
- Cared for a person with a life-limiting illness (end stage respiratory disease, end stage neurological disease, or end stage cancer).
- Bereaved within the last 5 years
- Participants must be informal carers (i.e. members of family or close friend¹³)

4.6 Recruitment of participants

Participants were gained from a wide range of sources. In total, 54 organizations were contacted. These included:

- Local (northwest) newspapers and media
- Local (northwest) patient and carer support groups and charities
- National patient and carer support groups and charities
- Local (northwest) carers' centers

¹² It is beyond the scope of the study to also assess the experiences of adults caring for children with life-limiting conditions, or children caring for adults with life-limiting conditions, as there are likely to be very different issues that would require more attention.

¹³ As defined in chapter one

In addition, posters were displayed around the university campus, a local supermarket community notice board and in a number of libraries in the northwest. A notice was also posted on the University of Liverpool announcements page. Participants were also gained through word of mouth and snowballing. This broad approach to recruitment was used in order to reach as many people as possible, in the aim of achieving a broad range of people with differing experiences.

Recruitment was largely focused in the North-West of England, due to limited funding for travel. Telephone interviews were conducted with two participants who lived in the south of England.

The majority of organizations agreed to publicise the study via their newsletter, posters in the building and/or verbally (such as raising the issue in support meetings, for example). However, a small number of organizations declined to publicise the study, as they felt that it may be insensitive to patients with existing disease.

An encouraging response was gained from initially contacting local and national support groups (see Table 7). However, the researcher recognized that the experiences of patients and carers who belonged to a support group or charity may have differing experiences to those who do not. For example, participants gained through local support groups may have had more information about the disease, access to services, be informed about benefits and be better supported than those who are not part of such organizations. Local libraries and newspapers were then approached in order to gain participants with more varied experiences.

Recruitment increased rapidly on the publication a notice in a local newspaper (the Liverpool Echo). A small number of people who got in contact about the study were not eligible (for example, they were current carers; cared for children; were parents with a life limiting disease whose young children were caring for them; or were bereaved more than five years ago). In such cases, people were thanked for their interest before sensitively explaining that they would not be eligible to take part. A number of potential participants who left voice mails about the study forgot to leave a contact number or in some cases gave an incorrect telephone number. In these cases, participants' names were looked up in the telephone directory and followed up, or they were written to if they left an address.

Tables 7 and 8 indicate the diversity of the sample gained from this mixed method of recruitment.

Table 7: Source of recruitment

Source of recruitment	Number
Local newspapers/media	21
Local charity support group or newsletter	12
National charity support group or newsletter	1
Poster in public places (library, supermarket, hospital)	6
University announcement	7
Word of mouth and snowballing	4
Total	51

Table 8: Place of death by disease group

	Cancer	Respiratory	Neurological	Total
Home	10	6	3	19
Hospice	11	0	3	14
Hospital	5	4	5	14
Nursing Home	2	0	2	4
Total	28	10	13	51

4.7 Data collection procedure

Participants initiated contact with the researcher to express an interest in the study. Their suitability for the study was then assessed against the inclusion/exclusion criteria. Eligible participants received a verbal briefing about the study, over the telephone, and were sent a participant information leaflet in the post or via email. A follow-up phone call was made in the following week, answering any questions about the study that may have arisen from the participant information leaflet and to arrange a suitable time and place for the interview. The majority of participants elected to be interviewed at home. The following paragraph offers personal reflections interviewing participants in their own homes and in other environments;

Before beginning the interview, the participant and I often chatted informally about the study over a cup of tea. This often led to an informal discussion about the person they cared for. During these discussions participants often told me about their families and showed me photographs of the person they cared for. I felt that these informal discussions were very important in building rapport and allowed the participant to relax into the situation and

become comfortable with me. Participants often commented that they had not talked about their experiences for a long time, and accounts were often deeply personal. I felt that these informal discussions were very important, as they facilitated rapport and smoothly led on to extended in-depth narratives. I felt that this was attributed to feeling comfortable in their surroundings and comfortable with me as a researcher. Importantly, participants who were interviewed at home were also able to interact with their surroundings, and often appeared to relive their experiences through connecting with the memories around them in their home.

A small number of interviews were conducted at the University of Liverpool. Two interviews were conducted in a departmental meeting room, and one in a smaller 'breakout' room. *I felt that the interviews conducted at the university seemed more formal and began much more promptly than interviews at home, with little chit chat.* Interviews were generally held in the departmental meeting room. The 'breakout room' (small, office like room) was used for one interview, as a small sofa was available. On this occasion, the participant sat on the sofa, which has quite low, and the researcher sat on the desk chair. *On this occasion I felt that the environment affected the dynamics of the interview, instilling power dynamics between the researcher and the participant, in a doctor/patient like manner.* For this reason I decided that this room was unsuitable for future interviews, and further university based interviews were conducted in the departmental meeting room, which was large and airy. In all cases, consent forms were signed by researcher and participant. Interviews were taped using an Olympus digital recorder, with signed consent from the participant.

4.8 Qualitative Interviewing

A semi structured approach was initially taken to interviewing; a flexible interview schedule was developed,¹⁴ which acted as an aid to the researcher, who was relatively inexperienced in qualitative interviewing at the early data collection period.

The following paragraph offers a reflexive account of the use of this topic guide in the early fieldwork phase of the study.

Although an interview schedule (topic guide) had been devised for the study, I often found that only the first question was posed. What followed was often a chronological based narrative of the sequence of events, thoughts and feelings leading up to the person's death. I often used prompts to elicit more detail, or asked questions to provide clarification. Over time I began to be much more comfortable with this approach, as opposed to trying to keep to the structure of the semi-structured interview and I developed an understanding of the importance of allowing participants the room and flexibility to talk about what was important

¹⁴ See Appendix 4.

to them rather than what I was asking them. In some cases I felt that participants were almost 'bursting' to tell me their story, and in these cases in particular, I don't think it would have mattered what question I asked them, I would have almost certainly have got the story that they wanted to tell. In some cases I also felt that the story had been rehearsed; as if it had been played over and over in that person's mind and that the interview was an opportunity for them to tell their 'story'. In other cases participants were less open and asked "what do you want to know?" or commented that they were "not very good at talking" and felt more comfortable with more of a traditional 'question and answer' style interview. However in many of these cases I felt that the participant opened up as they got more comfortable with the interview situation, and the interview became more fluid.

It was therefore necessary to adapt the style of interviewing in light of the way that participants responded to questions. The topic guide was replaced by an open question; I asked participants if they could begin with the time around diagnosis and tell me about how the person's illness progressed. This proved to be a more suitable approach to interviewing in the majority of cases. This 'open' method of interviewing is often referred to as 'narrative' interviewing¹⁵.

Narrative interviews differ from traditional semi-structured interviews in a number of ways. Most notably, rather than the researcher devising an interview schedule and engaging the participant in a series of questions and answers, narrative interviews allow the participant the opportunity to tell their story as and how *they* want to and to focus on what was important for *them*. The researcher seeks to hear the personal experience of a person in regards to a particular part of his/her life (Kumar 2005). In this way, narratives offer the researcher the opportunity to understand the everyday experience of the participant and offer a greater insight into their lives than a semi-structured interview may allow. As Grinyer (2002) notes, this approach enables the 'researched' to dictate the content of the information shared to a greater degree than is possible in other methods of research .

Although the interviewing technique adopted in this study shares many characteristics with 'purist' narrative interviewing, the approach varied slightly on a number of its key principles, most notably, allowing the interviewee to decide how and when to begin and end their story (Kierans 2010).

Wengraf (2001) suggests narrative interviews be completed in a series of three subsessions:

1. session one allows the participant to tell their story

¹⁵ A narrative approach to interviewing is different to the narrative methodology that was described in the previous chapter.

2. session two allows the researcher to ask follow up questions based on the participant's account
3. session three (usually a separate interview) allows the researcher to ask the participant questions on issues that they may not have brought up in the initial interview.

The principles of subsessions one and two were adhered to in many of the interviews by allowing the interviewee to talk until they had finished, allow room for a break and then follow up with questions using their language and based on what I had been told. For example, I would thank the participant for telling me their story and explain that I had made some notes about what they had told me and ask if I could ask them about some of the things they had told me in more detail. Other principles of narrative interviewing were not obeyed as this was not intended to be a purist narrative study, such as following an interview schedule and asking participants a number of set questions, if they had not covered the issue themselves. Examples of such questions include those specifically relating to the physical, emotional and spiritual needs of the patient (and family) and bereavement support. In relation to Wengraf's (2001) notion of subsession interviewing, these questions would ideally be asked in a separate interview in subsession three. However, in the interviews they were asked at an appropriate time during the interview, such as when the participant was talking about their experience of palliative care.

As noted in the earlier reflective passage, there were a small number of cases where the participant initially struggled to be open and gave more of a chronological statement of events ("This happened and then this happened..."), leading up to the person's death. In these cases I attempted to adapt the interviewing style by drawing on the topic guide, using prompts and asking the participant if they could me more about particular aspects they had brought up in the interview. I believe that this approach was successful, as in these cases participants began to give more personalised and 'storied' accounts of their experiences.

In summary, although many interviews for this study have narrative qualities, some of the key principles of narrative interviewing were not adhered to. It is therefore more appropriate to refer to the style of interviewing used in this study as using a narrative *approach*, rather than 'purist' narrative interviewing. However, as asserted earlier, I felt that the interviews became more narrative in nature as I became more comfortable with the interviewing process and endeavoured to be sensitive to and respect the will of the research participant in the style I understood they wanted to be interviewed. This was achieved through a flexible and reflexive approach, which adapted to the needs of the participant and also the growing experience of the researcher.

4.9 Field notes

Detailed field notes were made as soon as possible after each interview. Field notes included notes on the background, setting and context of the interview, a summary of the issues that, at first glance, appeared most important to the participant and a summary of the key issues in the interview. Recording these thoughts and observations from interviews in such a way can therefore enhance data collection and analysis (Bluff 2005, p. 153). Field notes also offer the researcher an opportunity for self-reflection, such as how the interview went, reactions to situations or the disclosure of information and how the researcher may improve in the future (Berg 2007, p. 199). Personal reflections were recorded in a separate section in field notes (ibid).

When revisiting transcripts for data analysis, field notes served as a useful backdrop and reminder of the person, the context and the narrative presented. In this study field notes facilitated the data analysis process but did not form part of the formal analysis¹⁶.

4.10 Approaches to data analysis

A number of approaches to data analysis were considered prior to selecting a thematic structural analysis approach. As a novice qualitative researcher I explored a number of other approaches to data analysis in order to satisfy my own curiosity and embrace the opportunity to learn about the methods, their associated outcomes and the methodologies with which they are aligned. This section briefly discusses methods of data analysis that were rejected for use in this study (Interpretive Phenomenological Analysis (IPA) and Framework analysis) before introducing thematic structural analysis and providing a justification for adopting this method.

Interpretive Phenomenological Analysis (IPA) is aligned with phenomenology and was initially considered as a method of analysis in this study. IPA seeks to aid an understanding of the lived experience of participants and to uncover the fundamental character of an experience. Although this method is congruent with the phenomenological approach of the study, IPA is most suited to the analysis of case studies and small scale research studies of around ten or less participants (Smith et al 1999 in Reid, Flowers & Larkin 2005), due to the level of detail it seeks to achieve. It is therefore unsuitable to use in this study, which has over fifty participants, with most interviews between one and two hours in duration.

Framework analysis was also considered as a method of analysis for this study. Developed by the National Centre for Social Research, this method of analysis is particularly useful to aid policy and practice related research (Green & Thorogood 2004), where the aims and

¹⁶ See Appendix six for an example of field notes.

objectives are predetermined by the funding body (Pope, Ziebland & Mays 2000). A critique of the framework approach is that as objectives are largely determined at the beginning of a study, it uses a purely deductive approach based on these aims and objectives (Pope, Ziebland & Mays 2000), leaving little room for flexibility and interpretation. Framework analysis was therefore deemed unsuitable for this study, as this study seeks to understand the experiences and needs of carers and patients, requiring a more inductive and interpretive approach.

A number of approaches to data analysis were identified as being congruent with the aims of the research; these were thematic analysis, narrative analysis and thematic structural analysis. Upon further investigation, thematic structural analysis was identified as being the most appropriate method of analysis. The remainder of this section focuses on two methods of analysis that, when used together, form the analytical approach adopted in this study. This is depicted in the figure below.

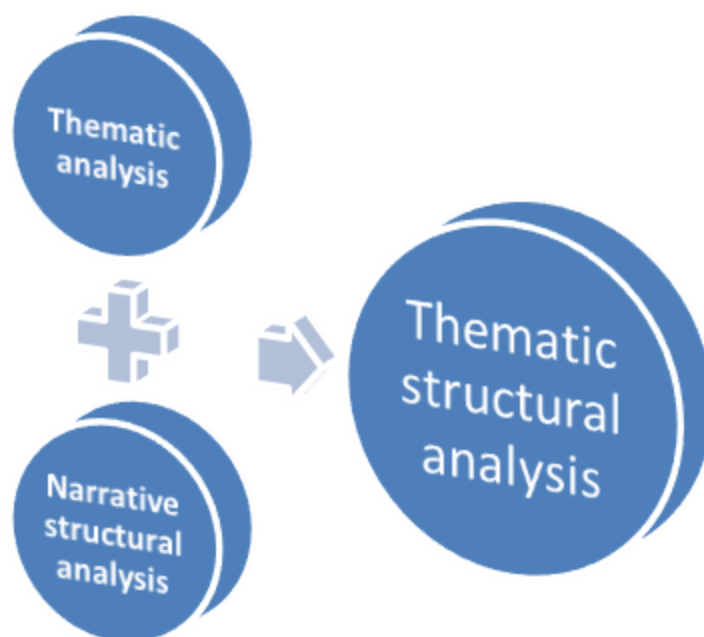


Figure 8: methods of data analysis

4.10.1 Thematic analysis

Thematic analysis offers an approach to analysis that is both structured and flexible. It focuses on identifying themes within data and can be applied successfully to large projects such as this, whilst maintaining sufficient level of detail. Braun and Clarke argue that thematic analysis “should be seen as a foundational method for qualitative analysis. It is the first

qualitative method of analysis that researchers should learn, as it provides core skills that are useful for conducting many other forms of qualitative analysis” (2006, p. 78). *I felt that this was an important point and that using this method, with appropriate rigor, would enable me to produce a good quality qualitative study and provide a sound basis for my future research career.*

Thematic analysis provides guidelines for analysis and yet is also flexible. Authors such as Braun and Clarke (2006) offer a six stage guide to data analysis, whilst Boyatzis (1998), (Silverman 2006) and Robson (2011) have also written extensively on the subject.

Thematic analysis has been described as a method of analysis which “enables scholars, observers, or practitioners to use a wide variety of types of information in a systematic manner that increases their accuracy or sensitivity in understanding and interpreting observations about people, events, situations, and organisations” (Boyatzis 1998, p. 5).

Thematic analysis does not subscribe to any one particular theoretical framework, unlike for example, grounded theory or IPA (Braun & Clarke 2006). Rather, it is a method of data analysis that is aligned with the interpretivist paradigm and lends itself well to analysis with roots in various philosophical positions, including phenomenology (Braun & Clarke 2006). Thematic analysis is therefore appropriately aligned with the philosophical stance of this study, as outlined in the previous chapter.

Fereday and Muir-Cochrane (2006) draw on Boyatzis’ (1998) method of thematic analysis and usefully describes a method of thematic analysis that analyses data both inductively and deductively. The development of inductive codes, influenced by Boyatzis, draws on the raw data itself. In contrast, the development of deductive codes are developed from the study’s research questions and the theoretical concepts of social phenomenology (Schutz 1967 in Fereday & Muir-Cochrane 2006). The aim of this approach is to provide a fuller and more complete understanding of the study under investigation.

Thematic analysis, as described here, was considered a useful approach, as often the researcher has some knowledge of possible codes and themes based on wider reading whilst conducting the literature review. This approach makes use of the researcher’s existing knowledge on the subject and is aligned with the philosophical framework of a study, whilst also being sensitive to the development of new knowledge, gained from participants’ subjective experiences. However, I wanted to explore other types of analysis as I felt that a ‘standard’ thematic analysis may fragment the data and that the meaning people attribute to events may be lost in this process (Riessman 2008). Thematic analysis may hold further

danger of fragmenting the data if analysis is assisted by a computer software package¹⁷ (Holloway & Todres 2005). To this end, narrative structural analysis and thematic structural analysis were explored in more detail and are described below.

4.10.2 Narrative structural analysis

A common criticism of traditional thematic analysis is that the practice of categorising data leads to fragmentation and loss of meaning (Riessman 2008). Rather than develop categories across cases, narrative thematic analysis strives to 'preserve sequences and the wealth of detail contained in long sequences' (ibid, p. 74).

Narrative structural analysis is concerned with *both* content *and* structure of narratives. In particular, this approach recognises that the meaning of an event is likely to be different to different people.

Labov's (1972, 1982) method of narrative structural analysis denotes that a "fully formed" narrative composes of six parts: abstract (summary); orientation; complicating action; evaluation; resolution; and coda (he notes that not all narratives must consist of all parts).

The emphasis on the interpretation of meaning in this approach is useful to this study, as the meaning attributed to different aspects of caring for a family member with a life-limiting illness is very personal and is indeed likely to hold different meanings to different people¹⁸.

4.10.3 Thematic structural analysis

The flexibility of qualitative research enables researchers to draw on the principles of more than one philosophy or method of analysis to make sense of their data. Indeed, Coffey and Atkinson (1996) advocate utilising the flexibility of qualitative analysis by employing complementary research strategies to explore qualitative data.

In this vein, thematic analysis and narrative structural analysis may be combined to enhance one another (Riessman 2008; Sparkes 2005). A benefit of this method is that it takes different meanings into consideration, allowing for the fact that the same issue or event may hold different meanings to different people (Riessman 2008). Thematic analysis allows only for an analysis of *what* was said, rather than *how* it was said and associated meanings (ibid, p. 90).

¹⁷ It was necessary to use a software package to assist in the management of data, due to the large amount of interview data.

¹⁸ Riessman (2008) provides a useful exemplar this method in her analysis of divorce stories. Long-term infidelity was a contributing factor to divorce in all three case studies, yet she identified that the situation held very different meaning and importance to participants.

In an example of the benefits of the utilisation of combined methods, Riessman was “able to describe broad patterns (thematic similarities across the sample) but also variation in meanings for individuals” (ibid). Riessman drew on her study on divorce to describe how, using this method, she was able to uncover how “infidelity was not an objective event, but a phenomenologically different experience” (Riessman 2008, p. 90). This method therefore allows the researcher to understand meaning as attributed to events by participants, rather than the researcher attributing meaning, as a thematic analysis may allow.

Riessman (2008) also advocates Robichaux’s use of combining thematic and structural narrative approaches in her PhD study (Robichaux 2003 in Riessman 2008). Robichaux began her analysis by identifying narrative units transcripts, before applying an adapted version of Labov’s structural narrative approach (ibid). Riessman reports that Robichaux identified that some interview data did not fit the narrative form, but highlighted that this should not detract from it being recognised as important data. By contrast, a purely narrative study may overlook these data, however Robichaux used a thematic approach to analyse data that did not fit the narrative structure, and then identified recurring themes across her data. She applied this approach to twenty-one qualitative interviews with critical care nurses in the USA. This approach was carefully considered; although the benefit of this approach is that all data is used in analysis, it is possible that classifying data as ‘narrative’ and ‘not narrative’ may disjoint rather than enhance an analysis.

This approach of combining structural and thematic analysis is very useful and was adapted to be more suitable for this study. The adapted approach involved undertaking a thematic analysis on a sample of transcripts and developing an initial coding framework. A structural analysis was then undertaken on a number of these transcripts, with the aim to enhance the thematic analysis and infer meaning. Further transcripts were then mapped onto the coding framework once validated. This method was deemed to be more suitable to this study, which has a large sample size and complex, extended narrative accounts.

Both thematic and narrative approaches were piloted on a small sample (n=3) of transcripts to facilitate a better understanding of the practical application of this approach.

First, interview tapes were listened back to, whilst following the transcribed text. Handwritten notes were then made, summarising the transcript and noting the themes that were interpreted as most important to the participant. Any other notes of importance, such as links between themes were also noted. A preliminary thematic analysis was then undertaken on the three transcripts. Themes were identified through both inductive and deductive methods.

Using Labov's approach, a narrative structural analysis was also conducted on these three transcripts. However, this approach to structural analysis felt rather clinical and created unease about whether stories fitted the conventions of a 'fully formed' narrative. I therefore drew on Mishler's (1986) approach of the 'core' narrative. A core narrative consists of the orientation (setting the scene; place, time, who was involved etc.), abstract (a short summary of the event), complicating action (actions or events that move the story along, and are presented as 'fact' by the participant) and resolution (outcome). The application of this narrative fitted well with my data. Additionally, it was observed that study participants offered a great deal of evaluation of events. On this basis it was deemed useful to also record 'evaluative' sections of responses by highlighting text within the core narrative categories.

Interpretation of meaning in narrative analysis allows for a more insightful analysis than other content analysis. Mishler provides a useful illustration of this point; drawing on an interview conducted with a participant about his marriage, Mishler noted that on first glance, the participant fails to answer his question and that the data was deemed 'irrelevant' and subsequently removed from the transcript (1986, pp. 234-235). However, when Mishler looked again at this response, this time through a narrative lens, he recognised the implied meanings of the story and the importance of the social constructs behind what is being implied. The value in narrative analysis is that in seeking to understand the meaning attributed to such accounts, it allows for a richer understanding of events and wider social factors.

Mishler asserts that such an analysis may allow for insights into 'the social structure of social relationships, about the rules governing how social status is affirmed, challenged, and negotiated, and about the ways in which the meanings of events and actions are expressed in language' (Mishler 1986, p. 240). He goes on to argue that such claims cannot be made through standard methods of analysis, where sections are isolated, fractured and fitted to a coding framework. He argues that narrative analysis 'contains the sequence of socially meaningful acts without which it would not be a story; its analysis therefore provides the basis for a direct interpretation of a complex unit of social interaction, in comparison to the standard approach where such interfaces are based on decontextualized bits and pieces' (Mishler 1979 in Mishler 1986, p. 241).

This triangulation of methods allowed for a richer understanding of the issues in the transcripts than either method would achieve alone. This approach was therefore deemed successful and adopted for the remainder of the analysis process.

4.11 Sampling thematic and narrative cases

This section discusses the sampling strategies and rationale for the sampling of thematic and narrative cases.

4.11.1 Sampling for thematic analysis

Fifty-one interviews were undertaken for this study. It was necessary to recruit this relatively large number of participants as the study originally set out to compare experiences between carers of people with neurological disease, respiratory disease and cancer. The sampling strategy was subsequently revised to be aligned with the research question.

All interviews were conducted, transcribed and carefully listened to by the researcher (see 4.12.1), which resulted in the researcher becoming deeply engaged with the data. In this way, all interviews contributed to the coding and final analysis, although the final number of transcripts coded in depth was revised down to thirty out of fifty-one.

Although qualitative research does not aim to make broad statements about the population under study it was important to ensure that the sub-sample represented the diversity of experiences of the full sample, and a maximum variation sample was adopted. Maximum variation sampling is based on a set of predetermined criteria and aims to maximise the quality of qualitative research by reflecting a diverse range of possible perspectives (Creswell 2007, p. 126). The maximum variation sample for this study was obtained based on the following criteria:

Table 9: sampling criteria

Gender of carer	Men were underrepresented in the sample (seven out of fifty-one), so it was important that men's experiences were represented as fully as possible in this study. All transcripts from male participants were included in the sample.
Age of the person being cared for	Age was considered an important factor in determining the sub sample. Age groups were based on the participant being of working age, retirement age or older adults. The age of a person is important to consider with regards to the research question because it may affect a person's ability to provide practical care.

Relationship between carer and patient (spousal, parent: child, child: parent)	The majority of caring relationships were spousal relationships or adult children caring for their older parents. A smaller number of cases were older adults caring for their adult children. There were also other family relationships such as mother-in-law/daughter-in law, for example. Less common caring relationships were included in order to gain a better insight into the varied experience of caring.
Place of death	A person's place of death was included as a characteristic for the sub sample because people are likely to have differing experiences of health care and death depending on where they die.
Diagnosis/ disease group	Disease group was included as a characteristic for selecting the sub sample as it is possible that different diseases are likely to have a different illness trajectory and may have differing access to services. Sampling cases by disease group was not straight forward as many participants cared for a person with multiple diagnoses. This characteristic is more common amongst older people, who are increasingly likely to live with multiple conditions (Dying Matters 2012).
Indices of social deprivation	<p>Social deprivation was also considered an important indicator as deprivation has a significant impact on a variety of health factors. People with higher deprivation are likely to die younger and have more disease (see for example Graham 2009; Naidoo & Wills 2005).</p> <p>The English Indices of Deprivation is the official measure of deprivation in England (Communities and Local Government 2010) and was employed as a measure social deprivation within the study. Using an indicator of social deprivation was considered retrospectively on the premise that different social groups are likely to varied resources available to them in terms of cultural capital (Bourdieu [1980] 1990, [1983] 1986). Indicators of social deprivation are useful as they provide further demographic insights on respondents. This serves both as an indicator as to the social demographic of those who participated in the study, but also allowed a maximum diversity sample to be obtained, in order to ensure that a wide spectrum of social groups are represented in this study.</p> <p>However, the index of multiple deprivation (IMD) guidance document notes that the score refers to a small geographical area rather than to</p>

	individuals. It therefore acts as an indicator of social deprivation rather than an exact measure of an individual's personal circumstances. Therefore IMD data must be treated with caution when utilised in this way (Communities and Local Government 2010).
Other	The number of transitions and degree of formal and informal support were also considered as possible sampling criteria. However, the number of transitions was not obtained from the outset or from a distinct point in time (e.g. last year of life) and was difficult to ascertain retrospectively from the interviews. Similarly, the level of informal or formal support is rather subjective and difficult to measure, so was not included in the analysis.

Further details of the cases sampled in this study can be found in Table 10.

4.11.2 Sampling for narrative structural analysis

The method of analysis outlined in this chapter required a sample of transcripts to be selected for narrative analysis. A narrative analysis was conducted with three transcripts (Catherine, Pat and Janet). These transcripts were selected on the basis of the richness of their stories, as this would be most helpful with understanding and interpretation of events. It was duly noted that people's capacity to tell, to verbalise and articulate their stories may vary; for example, it is possible that those who provided rich and articulate narratives may be the most well educated, and therefore may bias the sample. Conversely, storytelling and narratives have traditionally been used as a method of giving a 'voice' to individuals from all backgrounds and cultures, as a narrative approach draws on personal accounts and experiences rather than education and literacy. Indeed, storytelling is considered a traditional practice; a practice that is passed down from generation to generation in many cultures and is also instilled in us from an early age, often in primary school (Riessman 2008). This makes narrative an accessible method of communication for most of the population.

4.12 Data analysis procedures

This section documents the approach to data analysis. It is feasible that data quality was enhanced by documenting this process thoroughly.

4.12.1 Preparing data for analysis: transcription

Transcription is an interpretive process (Ellis 2009). It is therefore likely that each researcher will have a unique style, based on their personal interpretation. The majority of interviews

were transcribed by the researcher, whilst a small number were transcribed by another member of the research team. In order to ensure consistency across transcripts all transcripts that were not transcribed by the researcher were carefully listened back to and amended in accordance with the researcher's interpretation. All interviews were tape recorded, using an Olympus Digital voice recorder. Voice files were later transcribed using Olympus Digital software, according to the following protocol:

- Arial, font point 11, normal
- 1.5 line spacing
- Interviewer identified with 'I'
- Participant identified by 'P'
- Others identified as appropriate
- Place names, such as towns, cities, counties and countries were omitted and replaced with a letter and note i.e. W [country] or P [place].
- Hospitals, hospices, nursing homes, GP surgeries etc were also replaced with a character and a note i.e. R [hospital]
- Names were also anonymised using this system i.e. Dr. M, G [wife]
- Paralinguistics were placed in brackets i.e. [laughs], [whispers], [loudly], [quickly]. Extralinguistics such were also placed in brackets i.e. [telephone rings]
- Nonlexical expressions such as "mm", "mm hum", "er" were noted
- Local dialect, slang, swear words, abbreviated and omitted words were included in the transcript.
- Double quotation marks were used for reported conversations and single quotation marks were used for reported thoughts (and I thought 'how is this happening to us?')
- Break-offs (where someone stops or changes direction mid-sentence) were indicated using '-'
- Length of hesitations and pauses were indicated using '...' or '[long pause]'
- Emphasised words were italicised
- Unrecognisable words were indicated using [inaudible]

4.12.2 Application of data analysis

Each transcript was read and re-read and, in order to verify meaning, the original voice played back before hand-coding a hard copy of a transcript.

Thematic analysis

Initial codes were developed inductively, from the interview schedule, existing literature and the research question. Further initial deductive codes were then derived from three transcripts using the following procedure:

Gibbs (2007) suggests a number of descriptive and theoretical items to look out for when coding, alongside those more specific to your research approach and question. These include; specific acts or behaviours, events, activities, strategies, practices or tactics, states, meanings, participation, relationships and interactions, conditions or constraints, consequences, settings and reflexive passages (Gibbs 2007, pp. 47-48).

This study employed NVivo9 software to aid data analysis and to manage the data. Specific terminology, based on the analogy of a 'family' or 'tree' structure, is used to describe elements of the software. It is useful to define these terms before further discussing methods of data analysis.

Table 10: NVivo terminology: adapted from Gibbs (2002)

<i>Attribute</i>	A property of a node, case or document. Very like a variable in quantitative analysis. An attribute (e.g. gender) may have several values (e.g. male or female) and any particular node, case or document may be assigned just one value for each attribute.
<i>Annotation</i>	A short passage usually commenting on the contents of a document.
<i>Free Node</i>	A node which is not part of a node tree. Free nodes are kept as a simple list but may be moved to the node tree when required. This enables nodes to be created without having to worry immediately about how they relate to other nodes.
<i>Node</i>	In NVivo, an object that represents an idea, theory, dimension, characteristic etc. of the data. Text in documents can be coded at a node. Nodes can be linked to other nodes either directly or by position in a node tree and linked to documents.
<i>Node description</i>	Information about the node that is kept in the node property along with the name, creation date etc. and/or in a linked memo. It describes the idea, concept etc. the node represents.
<i>Theme(s)</i>	A set of ideas or concepts derived from theory or from respondents' lived experience which can be used to establish a set of nodes at which text can be coded.
<i>Tree Node (or</i>	The arrangement of nodes into a hierarchy, and so also known as a node

<i>node tree)</i>	hierarchy. At the top are one or more 'root' or 'top' nodes and arranged below them each may have one or more child nodes, which in turn may have their own child nodes etc.
<i>Tree</i>	The hierarchical, branching structure of tree nodes and case nodes.

NVivo employs a hierarchical system called a 'tree node' structure. This allows codes to be structured according to 'first' and 'second' level codes and beyond (see figure 9).

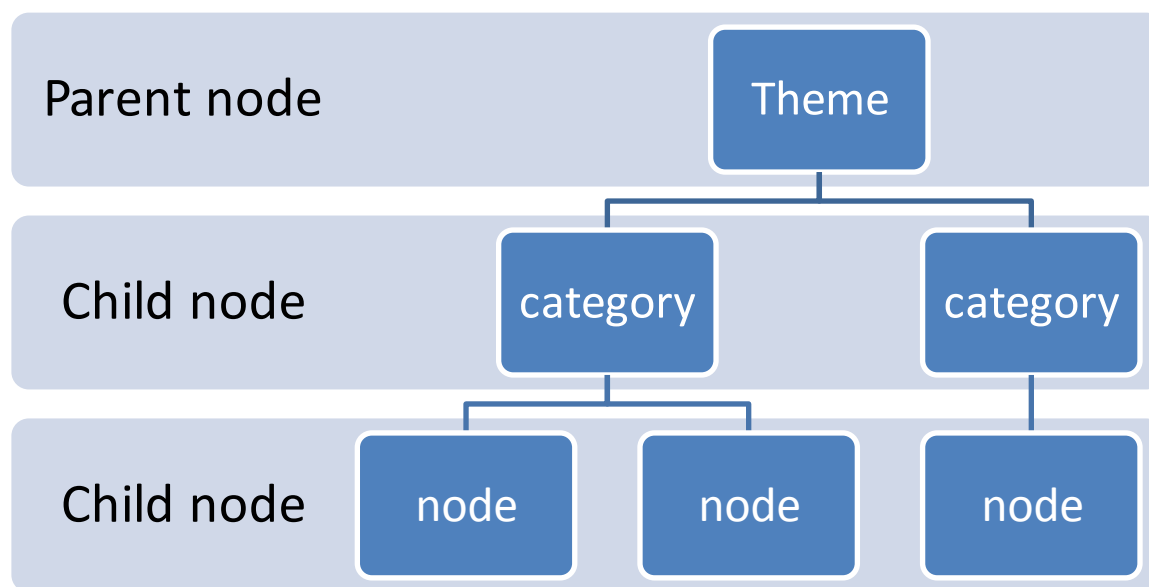


Figure 9: NVivo 'tree node' structure

A preliminary analysis of three transcripts was undertaken, whereby transcripts were read alongside each other and coding notes made in the margin. Following an NVivo training course, initial codes were devised and entered into the software. Annotations and node descriptions were also recorded within the software. This was useful as it facilitated the codes being able to be clarified and helped to maintain consistency throughout the coding process.

Abiding by this structure early on in the process became rather restrictive and was not conducive to the development of new ideas or codes. Rather, all emerging codes were set up as 'free nodes', meaning that all codes were assigned to the same 'level' coding in the first instance. Codes were then arranged into a suitable coding framework and arranged into an appropriate tier system at a later date.

In order to enhance the analysis and utilise the facilities of NVivo, orientation codes were developed to underpin the descriptive or theoretical elements of codes. Orientation codes may be described as *who, when, what, how and why*. In this study this translated to place of care, stage in illness trajectory and who was being spoken about, for example. Coding in this way helped to identify what was going on in the story by keeping the context in which the story is being told. Furthermore, this approach enabled a further exploration of the experience of caregiving in different care settings. An example of how this is useful is that, for example, the issue of 'dignity' may be explored according to the place of care.

Transcripts were printed and hand coded. Codes and sections from the paper transcript were then translated into NVivo. Line numbering facilitated this process. Sections of text required multiple codes, leading to a 'layering' of orientation, descriptive and theoretical codes.

The generation of categories was considered early on in the analysis process. This process involved printing off the list of codes, cutting them up and beginning to group them into natural categories. A large miscellaneous category was created initially, but this was worked through as the categories developed (see appendix eight).

Overarching themes were identified as this process developed. Notes were made where codes seemed to underpin numerous categories.

Seventy nine free nodes were initially developed, before being grouped into categories. These categories resulted in three main themes. Links between themes were tentatively made before being explored in more detail in later analysis. This process is documented in a series of images in appendix eight.

The 'queries' function¹⁹ was utilised in the thematic analysis. It was possible to build queries that focused on specific aspects of the data. Running a standard query on a child or parent node, would bring up every instance of data coded at this node. This was useful to get an overall picture of the data. Queries also allow the user to interrogate the data further. For example, it was useful to build a query that displayed all items of data that were coded at a parent node (e.g. 'reassurance') together with an attribute (e.g. 'cancer'), for example. Similarly it was possible to run a query using a parent node (e.g. 'reassurance') and an orientation code e.g. 'hospital' and then repeat this for 'home', 'hospice' and 'nursing home', so that comparisons could be made between groups.

¹⁹An advanced search facility that allows the user to explore their data. NVivo queries allow the user to 'find and analyse words or phrases in sources, annotations and nodes', and to 'ask questions and find patterns based on the coding'(QSR International 2013).

Narrative Structural Analysis

Narrative units were identified within a transcript, then plotted onto an excel table, under the appropriate headings for core narratives (described in section 4.10.3). Evaluative comments were also highlighted in the text. Although outside Mishler's 'core narrative' participants' evaluative comments offered valuable insights into their interpretation of events.

Each narrative unit was summarised in the 'my interpretations' column before asking the question *what is the point of this story?*; that is, the researcher's 'interpretation of the story's point, that is, what I think the narrator intended to communicate as the meaning of the account' (Mishler 1986, p. 236). This is essentially the value of narrative research, as the 'point' of the story is rarely explicitly expressed by the narrator (ibid).

Narrative units often contained additional mini narratives within them. These mini narratives were broken up within the main narrative, to aid the interpretive process. The question 'what is the point of this story?' was posed to each mini narrative, whilst additional broader interpretations were made of the narrative unit as a whole. An example of the analysis can be found in Appendix 7.

Frank (cited in Rolls, Payne & Brown 2009) commented that 'any story always comes from other stories and leads to still more stories' (preface). This was certainly the case in this study and required the careful consideration in order to establish where one story ended and another began. The framework of narrative structural analysis provided a useful structure that aided this process.

'Within story' interpretations and 'whole story' interpretations enabled the main points of the stories to be drawn out and compared across narrative cases. Similarities and differences were then looked at in more detail²⁰.

Narrative analysis also provided a greater understanding of overarching themes in the thematic analysis and led to a greater insight into links between themes. Further details of the this process can be found in Appendix 8.

Three key themes emerged from the data using this approach to data analysis. These were:

- 1) Roles & Relationships
- 2) Uncertainty & Reassurance
- 3) Communication.

These themes will be discussed in more detail in the findings chapters.

²⁰ An example of the method used in this study is given in appendix 3.

4.13 Issues of quality

The terms 'reliability' and 'validity' are often discussed in relation to the quality of the research aligned with positivism and the natural sciences. Alternative terms such as 'trustworthiness' and 'authenticity' (Lincoln & Guba 1985) are often favoured within the interpretivist paradigm and in qualitative writing. Whether quantitative or qualitative, issues concerning the quality of research are important as they enable the reader to verify the authenticity and appropriateness of the study and evaluate research findings.

Lincoln and Guba (1985) and Guba and Lincoln (1989) suggest that quality in qualitative research may be assessed by assessing the 'trustworthiness' of a study. They put forward four points for establishing trustworthiness in naturalistic inquiry. These are: credibility, transferability, dependability and confirmability, and are described in Table 11.

Credibility is an additional dimension of quality in qualitative research. It refers to the level to which it is accepted that what people say is true, in terms of their perception of events, opinions etc. (Holloway & Wheeler 2010). The acceptance of believing what participants say to be true is particularly important to this study, as it allows the phenomenon to be understood from the participants' perspective; as Nolan (2001) notes, 'the circumstances of care being the less important than a carer's perception of them' (p. 94). In this study, credibility was sought by undertaking narrative style interviews and by using a structural-narrative approach to analysis. These methods aim to achieve an in-depth understanding of participants' experience.

The practice of member checking (Lincoln & Guba 1985) was also employed in this study. This was achieved by sending a copy of the transcribed interview transcript back to participants to verify that the intent was correct (this can also be referred to as internal validity). The majority of participants agreed that the transcript was a true representation of the interview and that no changes were necessary. A number of participants were able to identify several 'inaudible' words from the transcript and others identified minor corrections:

Page 6: 'Happily she might have dealt with everybody else' should, I think, read 'Perhaps she might have dealt with everybody else OK'

Page 18: 'I was able to take on board' should read 'I wasn't able to take on board'

(Excerpt taken from email correspondence with Jane)

These examples demonstrate the value of participants being able to verify the written product of the interview and show how easily minor errors, resulting from mishearing the tape, can change the meaning of what is being said.

In addition, the practice of peer review or 'peer debriefing' (Lincoln & Guba 1985) was undertaken; all participant transcripts were read by the primary supervisor and the researcher partook in group data analysis sessions with student peers. In these sessions researchers would take it in turn to present an aspect of analysis that they were struggling with or sought further advice on. Peer review facilitated useful discussions and further insights into the data.

Reflexivity may also be considered a factor contributing to quality in qualitative research, as a critical awareness of one's role as a researcher, relationships with participants and prior assumptions, for example, enhances a study's credibility and dependability (Holloway & Wheeler 2010). A reflective approach to research was taken throughout this study, for example, through the use of field notes and a research diary. Reflexive passages are offered throughout the thesis.

Table 11: Establishing trustworthiness (adapted from Holloway & Wheeler 2010, pp. 302-304)

Term	Criteria	How this was achieved
Dependability	Consistency and accuracy of findings achieved through transparent recording of decision making.	A research diary was used to document decision making rationale. Notes from the diary were utilised in the writing up process to ensure clarity with regards to the decision making process throughout the thesis.
Credibility	Participants are included in the research process by having the opportunity to verify the interpretation of transcripts or findings.	Member checking.
Transferability	Findings may be transferred to other similar situations or with similar groups of participants.	The findings documented in chapters six to nine are discussed in relation to other research in the field. Data triangulation was employed in this study; this included the relationship between the carer and the cared for person; the diagnosis of the cared for person; the age and gender of the participant and the person they cared for; and place of death. The diversity of the participants in this study is documented by the provision of a short summary about each participant in the following chapter. Such diversity may allow for an in-depth analysis of the phenomenon under study.
Confirmability	Data can be traced back to its origins.	An 'audit trail' from raw data to the development of codes, initial categories and themes has been documented in this chapter (and is evidenced in appendix eight). This process was not done in isolation; all interviews were transcribed and shared with my primary supervisor. The development of codes and themes were also shared and discussed with both supervisors in the development stage. The interpretation of data was also discussed with supervisors throughout the analysis stage. In this way, the analysis process has also been subject to 'peer review' as defined by Holloway and Wheeler (2010, pp. 307-308)

4.14 Summary

The evolving nature of this study led to a careful examination and justification of the methods employed. In this chapter I have endeavoured to provide a transparent discussion of the decisions that were made and the processes of thematic structural analysis.

Ethical issues have been explored in detail, reflecting the importance of this issue in this study. The issues of subjectivity and reflexivity have also been explored, providing the reader with an insight to the researcher's positioning. Finally, issues of validity in relation to qualitative research have been discussed in order to allow for a critical evaluation of the research to take place.

Having provided a detailed background to study, the following chapters present the main study findings.

Chapter 5

Introduction to the Findings Chapters

This chapter precedes the findings chapters and provides information about the participants who took part in this study. The chapter summarises participant demographics and provides background information about all participants. Vignettes are presented in order to provide a more personalised introduction to study participants. In keeping with the interpretive approach, this information aims to contextualise the data presented in the findings chapters. The chapter concludes by introducing each of the findings chapters and explaining how these chapters are organised.

5.1 Demographics of study population

Fifty-one participants were interviewed for this study between July 2009 and July 2011. Forty-three of the family caregivers interviewed were female and eight were male. There were a range of caring relationships, which included: adult daughters caring for an older parent (n=20); daughter-in-law caring for her mother-in-law (n=1); husbands caring for their wives or partners (n=5); wives caring for their husbands or partners (n=18); mothers caring for an adult child (n=2); sister caring relationship (n=1); sister-in-law caring relationship (n=1); adult sons caring for an older parent (n=3).

Participants were recruited from a variety of sources and are broken down as follows: word of mouth (n=3); university announcements (n=7); snowballing (n=1); radio (n=1); poster in local hospital (n=3); through notices in charity newsletters/websites (n=14); through posters in local libraries (n=2); local newspapers (n=20).

Twenty-eight participants cared for a relative with cancer; 13 cared for a person with a neurological condition; and 10 cared for a person with a respiratory condition. These however were not discreet categories; many participants had more than one condition e.g. lung cancer and Chronic Obstructive Pulmonary Disease (COPD), or had multiple cancers.

Nineteen participants cared for a relative who died at home; 14 in a hospice or specialist palliative care ward of a hospital; 14 in a hospital; and 4 in nursing homes.

The number of years a person cared for their relative is provided where possible, however, many participants found this a difficult question to answer (which resulted in some missing data). Interestingly, this question often led to participants beginning their narrative rather than eliciting the expected of response i.e. 'around two years'. This offers a further insight into how family carers may view their role and how it changes over time.

Thirty-three participants chose to be interviewed in their own home; 13 participants were interviewed in the university; 1 participant was interviewed at the university and then followed up over the telephone; 2 were interviewed in their place of work; and 2 were interviewed over the telephone.

Interviews lasted between 30 minutes and three and a half hours. On average, interviews lasted for around one and a half hours (median).

5.2 Whole sample demographics

Table 12: Sample Demographics

Pseudonym	Relations hip to Patient	Health Condition	Place of Death	Patient DOB	2010 IMD score of lower SOA	National rank of lower SOA ²¹	Participant recruited from	Sample
William	Son	Neurological (Parkinson's with Lewy bodies Dementia)	Hospital	1940	4.3	30749	University announcement	
Haley	Daughter	Neurological (Parkinson's Disease)	Hospice	1929	36.1	5826	University announcement	✓
Nina	Daughter	Cancer (pancreatic)	Hospice	*	6.9	27973	University announcement	
Harry	Husband	Cancer (brain tumour, lung cancer)	Home	1946	36.1	5842	Newspaper	✓
Pat	Wife	Cancer (brain tumour)	Hospital	1946	7.2	27599	Radio advert	✓
Christopher	Son	Cancer (Prostate)	Hospice	1928	7.2	27599	University announcements	✓
Alison	Wife	Respiratory (Pulmonary Fibrosis)	Hospital	1936	16.3	17063	Newspaper	
Joanna	Daughter	Cancer (Lung)	Home	1928	46.9	2799	Poster	✓
Barry	Son	Cancer (Ovarian)	Home	1936	30.8	7839	Newspaper	✓

²¹ 1=most deprived in England, 32,482= least deprived in England

Ann	Daughter	Neurological (Progressive Supranuclear Palsy)	Hospice	1938	22.3	12303	Newspaper	✓
Diane	Wife	Neurological (Progressive Supranuclear Palsy)	Home	1926	3.8#	1866~	Advert in local newsletter	✓
Geraldine	Daughter	Cancer	Nursing home	m 1938 f 1931	19.2	14607	Advert in local carers newsletter	✓
Katrina	Daughter	Cancer (small cell lung cancer)	Hospice	1933	53.7	1593	Advert in local carers newsletter	
Jane	Daughter	Respiratory (Lung fibrosis)	Home (Sheltered accommod ation)	1927	5.5	29497	Poster in library	✓
Julia	Daughter	Neurological (Lewy Bodies disease)	Nursing home	1915	19.4	14493	Newspaper	✓
Robert	Husband	Respiratory (Pulmonary Fibrosis)	Home	1932	17.2	16290	Advert in local mobility newsletter	✓
Bridget	Wife	Cancer (prostate) and Respiratory (COPD)	Home	*	49.6	2259	Newspaper	
Esther	Daughter	Cancer (lung and bowel)	Hospital (Palliative care ward)	1929	6.3	28663	Advert in local carers newsletter	
Pauline	Wife	Cancer (small cell lung)	Hospital	1949	17.2	16290	Advert in local	✓

		cancer) with brain metastasis	(palliative care ward)				carers newsletter	
Lisa	Daughter	Cancer (Endometrial) and metastasis	Home	1923	29.5	8422	University magazine	
Nicola	Daughter in law	Cancer (Ovarian)	Home	1923	14.7	18525	Poster in local Hospital	✓
Suzanne	Daughter	Respiratory (COPD)	Home	1938	10.9	22799	University announcements	
Sarah	Daughter	Cancer (colo rectal)	Home	1927	*	*	University announcements	
Louise	Wife	Neurological (Parkinson's)	Hospital	1940	12.8	20597	Advert in Neurological charity newsletter	✓
Samantha	Daughter	Cancer (Lung) and Respiratory (COPD)	Hospital	1926	6.3	28663	Poster in local hospital	
Natasha	Daughter	Cancer (Lung)	Home	1934	66.4	395	Neurological charity newsletter	
Sharon	Wife	Neurological (PSP)	Home	1944	3.8	31172	Neurological charity website	✓
Linda	Wife	Cancer (Leukaemia and prostate)	Home	1943	9.3	24914	Word of mouth	✓
Helen	Wife	Respiratory (COPD)	Hospital	1944	71.1	190	Respiratory disease support group	✓
Claire	Wife	Cancer (Liver) and	Hospital	1934	26.6	9822	Respiratory	✓

		Respiratory (COPD)					disease support group	
Leah	Wife	Cancer (brain tumour)	Hospice	1955	19.9	14096	Word of mouth	
Catherine	Wife	Neurological (MS) and Cancer (Colon)	Hospital	1947	6.2	28734	MS Society Newsletter	✓
Elaine	Wife	Neurological (Parkinson's)	Hospital	1928	6.2	28734	Word of mouth	✓
Karen	Wife	Respiratory (COPD and emphysema)	Hospital	1933	19.5	14355	Respiratory disease support group	✓
Natalie	Wife	Neurological (MS)	Home	1934	3.1	31747	MS Society Newsletter	✓
Bill	Husband	Cancer (Ovarian)	Hospital	*	8.4	26050	Newspaper	✓
Graeme	Husband	Neurological (MND)	Hospital (Palliative care ward)	1967	47.2	2737	Newspaper	✓
Rachel	Sister	Cancer (ovarian)	Hospice	1972	46.9	2788	Newspaper	✓
Hazel	Daughter	Neurological (Dementia)	Hospital	*	59.2	888	Newspaper	
Janine	Wife	Cancer (mesothelioma)	Hospice	1926	9.4	24838	Newspaper	
Mary	Wife	Respiratory (COPD) & Cancer (lung)	Home	*	55.3	1364	Newspaper	
Charlotte	Sister in	Cancer (Liver)	Hospital-	1953	45.6	3099	Newspaper	

	law		Palliative care ward					
Sue	Daughter	Cancer (Throat)	Nursing Home	*	65	467	Newspaper	✓
Jean	Daughter	Respiratory (COPD)	Home	*	53.2	1662	Newspaper	✓
Rosemary	Wife	Cancer (non-Hodgkin's lymphoma) Also had COPD and neurological (stroke)	Hospital	1945	71.8	174	Newspaper	✓
Marie	Daughter	Neurological (CBL)	Nursing Home	*	23.2	11740	Newspaper	✓
Carol	Mother	Cancer (stomach)	Home	1975	45.6	3099	Newspaper	✓
Stephanie	Mother	Cancer (breast and brain metastasis)	Hospice	1966	20.3	13789	Newspaper	✓
Paul	Husband	Cancer (ovarian)	Hospice	*	15	18209	Snowballing	✓
Christine	Daughter	Respiratory (COPD)	Hospital	1929	22.9	11973	Newspaper	
Janet	Daughter	Respiratory (COPD and emphysema)	Home	*	35.6	6012	Poster in library	✓

* missing data

~National rank of lower SOA 1=most deprived in Wales, 1,896= least deprived in Wales

2008 Welsh IMD score of lower SOA

5.3 Introduction to participants

This section introduces the reader to the participants who took part in this study. The vignettes that follow are based on demographic information gathered before the interview and from field notes. The vignettes include information on the relationship between the carer and their relative, their family situation, the cared for person's place of death, and other relevant information to their caring experience. The aim of these vignettes is to introduce the reader to the participants of this study and, in line with the interpretivist paradigm, to provide a context for the quotes drawn upon in the forthcoming findings chapters.

Alison

Alison cared for her husband who had Pulmonary Fibrosis (a respiratory condition). She was a nurse at a local hospital and had taken time off work on sick leave to care for her husband (she also suffered from her own health problems during this time). Alison and her husband had adult children but they had families of their own and were not involved in their father's day to day care. Alison's husband had generally been quite well during his illness, but deteriorated very quickly in the last few weeks of his life. He died in hospital.

Ann

Ann considered herself to be the secondary carer of her mother, who suffered from the neurological condition Progressive Supranuclear Palsy (PSP). Ann considered her mother's second husband to be the primary caregiver because he cared for her in their home throughout her illness, until the final two weeks of her life, where she was cared for in a hospice. Ann found it very difficult to manage the relationship between her and her mother's husband (as he was not her father), as they sometimes had conflicting views about her care and what was best for her.

Barry

Barry lived with his mother for many years prior to her diagnosis of ovarian cancer. Barry explained that his mother was a very private lady and did not disclose her diagnosis to him for some time. Barry's mother had several hospital stays but strongly felt that she wanted die at home. During her time in hospital she also instructed the doctors not to tell her sons (who were in their forties and fifties) details about her illness. As such, Barry's knowledge of his

mother's illness, treatment, the provision and quality of her care was somewhat limited. Barry and his mother were supported at home by daily visits from formal carers and district nurses, who provided the majority of care for Barry's mother. In keeping with his mother's wishes, Barry had a limited hands on role in his mother's care. Barry was supported by other family members and his partner throughout his mother's illness.

Bill

Bill cared for his wife, who had ovarian cancer. Bill had recently retired from work, so was able to care for his wife full time. His wife left her job due to her illness. Bill's wife received palliative chemotherapy and was cared for at home by Bill. She attended the palliative care ward of a local hospital as an outpatient, during this time, but was later admitted as an inpatient. Bill and his wife had two grown up children, who were with him during the last days of his wife's life. She died in the palliative care ward of the hospital.

Bridget

Bridget cared for her husband who had prostate cancer and respiratory disease (Chronic Obstructive Pulmonary Disease or COPD). He was diagnosed with this condition nine months before his death. Bridget and her husband were an older couple and had limited support from family and friends (Bridget did not talk about any other family members apart from mentioning her husband's sister in passing). With the exception of a number of short stays in hospital, Bridget cared for her husband at home. Her husband died at home. The district nurse visited regularly to change her husband's catheter. Overall Bridget felt that she and her husband received very poor care and support and had lodged a number of complaints with the health authorities involved in her husband's care.

Carol

Carol cared for her son who was diagnosed with cancer of the stomach in his early thirties. She was interviewed two years after his death. District nurses visited Carol's son at home during his illness. Additionally, her son was offered support from the Macmillan nurses, but he refused their support until very late in his illness. This was very difficult for Carol, as she found it very hard to cope with her son's symptoms at home with little support from health professionals. Carol was told repeatedly that her son needed to request the support and that

it could not be accessed through family members, even if they were the person's main carer. Having rejected support in the early stages of illness, Carol and her son found it difficult to access care and support further on in the illness trajectory. Carol felt that there was a lack of support at the end of life. Carol had two daughters who lived nearby who were able to help care for their brother. A family friend was a district nurse and provided some additional advice and support to the family when she was off duty.

Catherine

Catherine's husband was diagnosed with Multiple Sclerosis (MS)²² in the early 1980s. As his illness progressed and he became less independent Catherine became his main carer. Catherine's husband was also diagnosed with colon cancer two weeks prior to his death. Catherine cared for her husband with the assistance of formal support from a private care agency so that she could continue to go to work part-time. She also arranged for a number of major adaptations to be carried out on their home in order to improve accessibility for her husband and his wheelchair and to ensure that he could remain at home for as long as possible. Catherine and her husband each had two children from previous marriages. Catherine's (adult) step daughters did not live locally. They had a number of close friends who were also very supportive.

Charlotte

Charlotte cared for her sister-in-law for a year before her death. Charlotte's husband and their two children also helped where they could). Her sister-in-law was in her early fifties and had a rare form of liver cancer. Charlotte worked part-time but found it difficult to balance her work, family, household chores as well as caring responsibilities and a second household. Charlotte's husband worked full-time, so was limited to how much he could contribute. Charlotte described there being temporary support from a social worker, but no other health or social care through the duration of her illness. A Macmillan nurse had contacted in the last weeks of her life. Charlotte's sister-in-law had three temporary stays in the palliative care ward of a local hospital and died on her final admittance.

²² MS is a long-term condition which affects nerves in the brain and spinal cord. This leads to difficulties with muscle movement and vision (NHS Choices 2013c).

Christine

Christine helped to care for her elderly mother, who had Chronic Obstructive Pulmonary Disease (COPD). Her mother had been diagnosed with this condition thirteen years prior to her death, with Christine being her main carer in the final four years. Her mother lived in sheltered accommodation, but had had many hospital admittances during the course of her illness and particularly so in the final years of life. These were concerned with breathing difficulties connected with her condition. Upon leaving hospital her mother was supported at home by a respiratory team and specialist nurse for a six week period. She died in hospital on her last admittance.

Christopher

Christopher's parents were in their late 70's and lived about an hours' drive away. As such, it was difficult for him to support his parents on a day to day basis. Christopher also worked full-time and had a young family of his own.

His father suffered from prostate cancer²³ and possible Labyrinthitis (dizziness). He also had a condition which affected the use of his tongue, inhibiting his speech and eating, which he found distressing. Christopher explained that his father was not treated for his cancer because of his age. Christopher's mother cared for her husband, with the help of other family members, at their home until additional help was required. This additional support was provided by through social services. Christopher's father was taken to hospital when his condition deteriorated, where he stayed for several weeks. The participant's family then arranged for a place in a hospice, where he stayed for around a week before he died.

Claire

Claire's husband had suffered from chronic obstructive pulmonary disease (COPD) for thirteen years. He was admitted to hospital suddenly with suspected appendicitis. Further investigations in hospital led to the discovery and diagnosis of liver cancer, of which he died six weeks later in hospital. Claire's husband had lived independently up until this hospital admittance and Claire had not considered herself to be his 'carer' as such. Claire was keen to help care for her husband in hospital and took care of his personal care where she could.

²³ The prostate is a small gland located near to the bladder in men (NHS Choices 2013f).

Claire was also a volunteer for a carers' charity, which meant that she was well informed on many aspects of caring, such as infection control and relevant policies and procedures.

Diane

Diane cared for her husband at home throughout the majority of his illness. Her husband was diagnosed with a neurological condition, but a formal diagnosis of PSP was not reached until post-mortem. Diane's husband had several short respite stays in the palliative care ward of the local hospital, but died at home. Diane is a former nurse and took the decision to take on much of the responsibility for her husband's care and refused support from district nurses and formal carers.

Elaine

Elaine's husband died a year prior to the interview with dementia with Lewy-bodies²⁴. She was her husband's main carer and was in her late seventies. Elaine and her husband also had two daughters who visited quite frequently, but were not involved their father's day to day care. Elaine was offered some additional support from social services, but the timing and quality of care were not suitable for their needs. Elaine paid for private carers to come in at times which were more suitable for her. Her husband was admitted to hospital on a number of occasions as his illness progressed. He died in hospital around a week after his final admittance.

Esther

Esther cared for her father for six years, when he was first diagnosed with bowel cancer. This was successfully operated on, but he developed lung cancer some years later. Esther was supported by immediate and extended family to care for her father, and described there being a 'rota' system in place to help manage work and home commitments. Esther and her family cared for her father at home until the last few weeks of his life, when he was admitted into a designated palliative care ward of a local hospital, where he later died.

²⁴ A common form of dementia which causes people to experience problems with memory and a variety of other symptoms (NHS Choices 2013a)

Geraldine

Geraldine cared for both of her parents over the same period of time. Geraldine's mother suffered from lung cancer and brain metastases, whilst her father suffered from bowel cancer. Geraldine had multiple caring responsibilities, as she was also the main carer for a close friend. Geraldine's parents lived together in their own home for as long as possible before a change in circumstances led them to live in nursing homes close to their daughter. Geraldine had a large family, with lots of brothers and sisters. She commented that it was useful to have a wide support network but that having a large family also often caused fractions regarding decision making about their parents' care. Geraldine identified herself as a 'carer' and was knowledgeable of the support that was available to her and was a member of a local carers' support group. She had also attended courses that led her to feel prepared for her role as an informal carer.

Graeme

Graeme's wife suffered from Motor Neurone Disease. He cared for her at home for as long as possible, with little help from others (his wife had refused help from outside agencies and other members of her family were not involved in caring for her). Graeme's wife had several respite stays in a palliative care ward of a local hospital and was later admitted as an inpatient, where she died. Graeme and his wife were in their early forties and had school aged children.

Haley

Haley cared for her mother, who had Parkinson's disease. Her sister was very involved in their mother's care and they also had a brother who helped but lived far away. She had various difficulties in securing appropriate care for her mother. She eventually secured a place in a nursing home for her mother where she lived before being admitted into a hospice, where she died.

Harry

Harry was an older gentleman and was the primary carer for his wife, who died from a malignant brain tumour. Being in his 70's Harry found that caring for his wife was sometimes

difficult. Lung cancer was stated as the cause of death on his wife's death certificate, although this was never formally diagnosed during her illness. Harry's wife was in hospital for much of her illness, but he took the decision to bring her home and care for until her death, referring to this as a 'family thing'. Harry was supported by both his family, who lived locally, and formal services, including a MacMillan nurse.

Hazel

Hazel cared for her mother, who had dementia, and her father, who had Leukaemia. Her father died in 2007 and her mother in 2009. Although she spoke about caring for both of her parents, she predominately spoke about caring for her mother, as this was a more recent experience. She cared for her mother at home but she was later admitted to hospital with pneumonia, where she later died.

Helen

Helen had recently retired from her job in a local hospital when her husband became ill with chronic obstructive pulmonary disease (COPD) and a heart condition. She cared for him at home for five years, although he had frequent spells in hospital. Helen and her husband attended a local lung disease charity support group, which they found to be of great support in terms of both emotionally and practically in terms of information. She and her husband had a son who lived away and a daughter who lived locally but also had a family of her own to look after. Both children supported their mother emotionally during their father's illness but were limited in terms of the practical support they could assist with, as they had young families of their own. Helen did not drive but had a bus pass and used this to get to and from the hospital twice a day for visiting hours. Helen's husband died in hospital with his wife and children present.

Jane

Jane cared for her mother, who had a respiratory condition, for seven months before she passed away at home. Jane's mother lived in sheltered accommodation near to her daughter's home. Her father had passed away shortly before she began to care for her mother, as her mother's condition became much worse following her father's death.

Jane was married and visited her mother four-five times a week, with an additional support network of family, friends and neighbours, as well as formal carers. Having lived in the sheltered accommodation for a number of years she had friends and neighbours who would 'keep an eye on her' (as she described), as well as the residing warden. Jane's mother had several hospital admissions throughout her illness. On one occasion she was given an assessment and granted a care package to help with her needs at home, which consisted of a carer coming once in the morning and once in the evening to help her dress/undress and with meals. Her mother also had support from Health Care Assistants (HCAs) who were present in the sheltered accommodation and assisted her with a meal at lunch time.

The informal support network around Jane and her mother enabled her to maintain her employment and feel both practically and emotionally supported during this time, although she did not feel supported through any formal means. Jane also felt emotionally and spiritually supported through her church and church community.

Janet

Janet cared for her father, who suffered from emphysema and chronic obstructive pulmonary disease (COPD)²⁵. Her father had also had a heart condition and had two heart attacks in older age. Janet had been a full time carer for twelve years and had given up full time employment in a professional position to care for her parents. She had also supported her father in caring for her mother, who died with Alzheimer's disease ten years earlier. Janet's father lived independently in his own home throughout his illness, although Janet found that she spent increasing amounts of time in her father's house as his illness progressed. She felt that it was very important to support her father in maintaining his independence in his own home. Janet was a single mother with two teenage daughters and often found it difficult to manage two households. Janet received some support from her sister towards the end of her father's life.

Janine

Janine cared for elderly husband at home, with support from community nurses. Her husband had been diagnosed with cancer (mesothelioma²⁶) after experiencing

²⁵ Both are respiratory diseases

²⁶ A cancer affecting the lungs and abdomen. It can reduce the capacity of the lungs and lead to difficulties in breathing. This cancer can be caused by working with asbestos (Cancer Research UK 2013b).

breathlessness. The couple's son was a medical practitioner and had an understanding of the condition. Janine's husband was later admitted to a hospice for a temporary stay to sort out his medication, but his condition deteriorated and he died in the hospice.

Jean

Jean cared for her elderly mother who suffered from chronic obstructive pulmonary disease (COPD). Jean's mother had numerous short hospital admittances, but was mostly cared for by her daughter at home, in the home that they had shared for a number of years. Jean remained in full time work during this time, although this was very difficult at times. She and her mother were supported through social services, who provided a designated carer who would visit twice a day on week days. They were also supported by district nurses. Jean had several siblings, but they did not take an active part in their mother's care.

Joanna

Joanna cared for her mum, who had been diagnosed with lung cancer. She shared caring responsibilities with her sister, who was the main carer and who lived with their mum. Joanna is a trained nurse with many years' experience of working in hospitals and nursing homes. Joanna's mum lived over an hour away, resulting in frequent long journeys throughout her time as a carer. Interestingly, she described this journey time as time where she could be alone, have a cry and grieve for her mum. She told me that she felt she had done her grieving for her mum before she had died, as this enabled her to focus on her mum's wellbeing and care, where to a large extent she reverted to her role as a nurse and professional training. This was an interesting interview, as Joanna had multiple perspectives on care provision and the role of carers, informed by both her job and personal experience.

Julia

Julia's mother had a diagnosis of Parkinson's with Lewy Bodies disease. She supported her mother at home for as long as possible, until numerous falls and other complications led to several hospital admissions. Julia supported her mother's independence by helping her move into a 'halfway house' between supported accommodation and nursing home care. Within three weeks the 'halfway house' declared that they could not meet her mother's support needs and she therefore had no choice but to move into nursing home care. Julia was

emotionally supported by her family and friends during her mother's illness, with some of her friends regularly visiting her mother in the nursing home. Julia worked in the field of education and made many important points and interesting comparisons between the level of government funding and support available for children, compared with that available for the care of older people.

Karen

Karen cared for her husband who had chronic obstructive pulmonary disease (COPD) and emphysema²⁷ for fourteen years. Her husband's condition got progressively worse over time, with frequent acute episodes which required temporary hospital admittances. Karen was the sole carer for her husband. Some aids and adaptations were provided by social services and additional support was offered, but did not materialise. Karen and her husband had one son, who lived in another city. He was a medical professional and supported his mother whilst his father was in hospital before his death.

Katrina

Katrina and her daughter cared for Katrina's mother, who had a form of lung cancer. Katrina's daughter was a trained nurse and was very close to her grandmother. They cared for her in her own home for 11 and a half months after diagnosis. As the illness progressed, they required help from social services, who provided formal carers morning and evening, and three nights a week. Throughout this time Katrina's mother attended weekly day care at a local hospice, where she found out about a palliative care ward on at a local hospital. Her mother asked to go onto the ward for her medication to be assessed, but was there for three and a half months before passing away.

Leah

Leah had cared for her husband on and off for over 13 years. He had had numerous brain tumours during his life. His most recent brain tumour had affected his hearing, sight and aspects of his personality, making it difficult for her to continue to care for him at home. He was admitted to a general ward of their local hospital, before being moved to another hospital which could better cater for his needs. Complications arose regarding finding the most

²⁷ Both respiratory conditions

suitable place of care for her husband. He was transferred to a local hospice, where he was cared for for five weeks before passing away. Leah was also raising her young granddaughter.

Linda

Linda cared for her husband, who had a multiple diagnosis of Leukaemia²⁸ and prostate cancer. Linda felt that it was very important to her to carry out her husband's wish to be cared for and to die at home. She and her husband were approaching their sixties and were looking forward to spending their retirement together. Linda and her husband had adult children but they did not live locally. Linda was supported by a team of district nurses, who visited to at set times administer medication. They were also supported by a MacMillan nurse, who visited four times during his illness.

Lisa

Lisa cared for her mother, who had been diagnosed with endometrial cancer and metastasis in the lymph nodes and lungs. Lisa lived nearby and called in several times a day. In the last six months of her mother's life, District nurses visited monthly and then fortnightly. Lisa was her mother's sole carer, as her mother didn't want formal carers to help care for her. Her mother died in her own home.

Louise

Louise's husband had lived with Parkinson's disease for 20 years. His support needs became greater as his illness progressed. Louise did not have any support from formal carers, but was more concerned with the lack of support from family and friends, noting that she almost never asked for help from family or friends, and that equally none was offered. Louise's husband was cared for in hospital in the later stages of his illness and received palliative care.

²⁸ Cancer of the white blood cells

Marie

Marie cared for her mother for seven years. Her mother lived alone in sheltered accommodation and had numerous hospital admissions, before being moved to a residential home, where she died eighteen months later. Marie maintained a full time job in addition to caring for her mother.

Mary

Mary was an elderly lady and cared for her husband for one year before he passed away at home. Her husband had both respiratory disease (COPD) and lung cancer. Mary's grown up son also lived at home and also helped to care for his father. He was also present during the interview. Other family members also lived locally and supported Mary by taking turns sitting up with her husband during the night. Mary also had support from paid carers both during the day and four nights a week. Her husband had eight hospital admissions and one hospice stay during the last year of his life. He later died at home.

Natalie

Natalie was a retired nurse. She cared for her husband, who had Multiple Sclerosis (MS), a neurological condition. They received support from District nurses for around 15 years. In the last five years of his life they received additional health and social care support, five times a week. However, Natalie became unhappy with the quality of care and support they were receiving, and decided to hire a nurse privately, who visited 6 days a week. Natalie's husband was a medical professional, and a number of ex-colleagues and friends lived in the local area. Natalie felt supported by this, as she knew that she could call upon them, if needed. Natalie and her husband had a grown-up son and daughter, each with a family of their own. Natalie and her daughter cared for Natalie's husband at home in the days leading up to his death. During this time they were visited by District nurses, but Natalie explained that they only monitored his condition and did not provide any practical hands on nursing care.

Natasha

Natasha's mother was diagnosed with lung cancer 4 weeks before her death. She cared for her at home, with some support from district nurses. Natalie and her mother experienced lots of difficulties with the side effects of her medication, which she found very distressing. She was admitted to a hospice to have her medication assessed, but elected to return home in the final days of her life. She died five days later.

Nicola

Nicola was a trained nurse, but had not practised clinically for ten years. She gave up her paid work to care for a relative, and had actually cared for three relatives since leaving nursing. Nicola focussed on her experience of caring for her elderly mother-in-law, who had died two years earlier from ovarian cancer. Nicola and her mother in law were supported by Macmillan nurses at the end of life. Her mother-in-law died at home.

Nina

Nina cared for her mother, who had pancreatic cancer. Nina was an only child and, as her father was also elderly, she was her mother's main carer. There was a fairly short period of time between her mother's diagnosis and her death. Nina cared for her mother at home before she was admitted into hospital. Nina's father also died unexpectedly whilst her mother was in hospital. Her mother was then transferred from the hospital to a local hospice, where she died three weeks later.

Pat

Pat cared for her husband who had been diagnosed with a malignant brain tumour. She and her husband were both retired when he was diagnosed. They had two sons who lived nearby, but each had full time jobs and young families of their own, so were limited in the amount of practical support they could provide. Pat's sister in-law came to live with them for a short period, early in her husband's illness, but this was not sustainable in the long term due to her own commitments back home. Pat also had the support of paid caregivers and support from the community care team (district nurse support on request).

Paul

Paul's wife had ovarian cancer. He cared for her at home for under a year. He and his wife were supported by district nurses during this time. Paul felt supported by family, friends and members of their church. His wife was admitted into a local hospice so that her medication could be assessed. She came home, but was later re-admitted as an in-patient, and died in the hospice. Paul had been in full time employment prior to his wife's diagnosis. He was able to take compassionate leave for some months before opting to take early retirement.

Pauline

Pauline cared for her husband who had small cell lung cancer and brain metastases²⁹. She cared for her husband at home, but he had many hospital admissions due to the seizures brought on by his brain metastases. The presentation of neurological symptoms alongside diagnosis of lung cancer resulted in many difficulties in terms of his care both at home and in hospital. Whilst at home, Pauline and her husband were supported by a team of district nurses, a Macmillan nurse and their GP. They have two children in their twenties who lived at home, but no other family who lived nearby. Pauline's husband was admitted to a palliative care ward of a hospital towards the end of his life, where he later died. Pauline cared for her husband for 8 months before his death.

Rachel

Rachel cared for her sister, with the help of their mother. Rachel's sister was in her thirties when she was diagnosed with ovarian cancer. She also had a teenage daughter who the family helped to support. The family received little support from formal systems of care in terms of formal carers, but were visited frequently by district nurses. Rachel's sister had chemotherapy for many years before her treatment became palliative. During this time she built good relationships with staff at their local hospital. Rachel's sister was cared for in a hospice at the end of her life.

²⁹ Cancer cells form in the lung tissue and can cause coughing, shortness of breath and chest pains (NHS Choices 2013b). Brain metastases occur when cancer cells travel from the primary site to a secondary site.

Robert

Robert was the main carer for his wife, who had suffered from pulmonary fibrosis³⁰ for six years. She had passed away at home, a few months prior to the interview. Robert's wife had yearly check-ups at the hospital and also had several hospital admittances throughout her illness. She self-discharged from the hospital on her final admittance and a care package was arranged to provide support at home.

Robert and his wife had two adult children, who had professional jobs and young families of their own. Their daughter took a months' leave from work to help care for her mum when it became difficult for her father to cope alone. Their son lived in another city but was in regular telephone contact. Their son came up to help care for his mother in the last week of life and also provided some financial support. Robert was well known in his local community and felt supported by a close friend and neighbour.

Rosemary

Rosemary cared for her husband who had a multiple diagnosis of non-Hodgkin's lymphoma³¹, chronic obstructive pulmonary disease (COPD) and had previously suffered a stroke, leaving him with very limited mobility. She had cared for him at home for twelve years. Rosemary continued to work full time as her adult children lived close by and would keep an eye on their father. Rosemary's husband was at a high risk of developing pneumonia, which was indicated by infections and high temperatures. This resulted in many unplanned hospital admissions throughout his illness. Unplanned hospital admissions were minimised with the help of a specialist community matron (who was also present during the interview). Rosemary's husband later died of pneumonia in hospital, with COPD and non-Hodgkin's Lymphoma listed as secondary causes.

Samantha

Samantha was a trained nurse but now held a non-clinical role in a local hospital. She had cared for her father, who had lung cancer, melanoma (skin cancer) and Chronic Obstructive Pulmonary Disease (COPD). Prior to this diagnosis, her father also suffered from a number of other conditions and had rather poor health. He was admitted to hospital shortly after being diagnosed with lung cancer, where he also developed pneumonia and was moved to

³⁰ A respiratory disease.

³¹ Cancer of the lymphatic system, which is part of the body's immune system (NHS Choices 2013e).

intensive care. His condition improved and he was able to return home for around eighteen months. His health deteriorated again and he moved into a nursing home. He was cared for in the nursing home for one week before an emergency re-admittance to hospital, where he died the next day.

Sarah

Sarah's mother suffered from colo-rectal cancer. Her mother moved from her own home to live with Sarah and her family, where Sarah cared for her for four years. Despite her illness Sarah's mother remained relatively well and independent until 3 months prior to her death. She died at home. Sarah and her mother were supported by friends, family, Marie Curie Nurses and formal carers, who provided care through the night. District nurses also visited from time to time in the day, but they did not provide any 'hands on' care. Caring for her mother at home was very important, as Sarah explained that she knew her mother wanted to stay at home.

Sharon

Sharon was the main carer for her husband, who was diagnosed with Progressive Supranuclear Palsy (PSP)³². Sharon worked for the local city council and, as such, felt that she had knowledge of what she was entitled to and how to access services. Sharon eventually gave up her job as her husband's illness progressed. It was very important to Sharon care for her husband at home until he died. Sharon and her husband received regular support from a specialist Parkinson's nurse, who also arranged for additional home support from formal caregivers and Marie Curie nurses. Sharon's grown-up daughter also lived nearby and helped with care where she could.

Stephanie

Stephanie cared for her daughter, who was in her early forties, had breast cancer and brain metastases. Stephanie's daughter young daughter moved in with Stephanie and her husband so that they could look after their daughter and grand-daughter, whilst her daughter's partner worked. They were supported by Macmillan nurses at home, before Stephanie's daughter was transferred to a local hospice, where she died.

³² A neurological condition

Sue

Sue's elderly father had throat cancer. He was diagnosed in hospital and stayed there for a number of months until a suitable nursing home was found for him. He also spent one week in the local hospice whilst his medication was assessed. Sue and her sister visited their father as often as possible during his illness, but had some difficulties travelling to the nursing home on public transport.

Suzanne

Suzanne's father had suffered from breathlessness for a number of years prior to being diagnosed with Chronic Obstructive Pulmonary Disease (COPD). Her father's health declined steadily over a 10 year period, where he began to rely heavily on his oxygen and was unable to do household tasks. Her father had numerous hospital admissions over the years, due to chest infections, but had always been able to return home when he was well enough. Suzanne's father was under the care of a community respiratory team, who visited 'every few months', but there was no other support. Suzanne worked part-time and was a part-time student and was able to care for him in his own home. Her mother also had COPD, so had difficulty caring for her husband. Following his last hospital admittance, Suzanne's father was able to return home. He collapsed and died two weeks after returning home. There was no contact from the hospital or community nursing team in this period.

William

William's father had been diagnosed with Parkinson's disease with Lewy Bodies Dementia. He and his four brothers all helped to care for their father so that he could remain at home for as long as possible. William's father later moved into a nursing home but was later admitted to hospital, where he later died.

5.4 Presentation of results and organisation of themes

Three main themes were elicited from an in-depth analysis. These were; roles and relationships; uncertainty and reassurance; and communication. These themes form the basis of five results chapters:

Chapter 6 Roles & Relationships Part I

Chapter 7 Roles & Relationships Part II: roles and place of care

Chapter 8 Uncertainty & Reassurance

Chapter 9 Communication I

Chapter 10 Communication II: Experiencing 'care' in caring: the importance of compassionate care

These three themes are very much interrelated and run throughout the illness trajectory, from diagnosis, pre-end of life care, end of life care, to death and bereavement. However, certain aspects of each theme are specific to certain points in the illness trajectory. Such areas will be highlighted in the discussion of themes, as well as considered in recommendations.

The findings chapters are presented thematically and address the research question by demonstrating how formal and informal systems of care work together to meet the needs of patients and carers. The themes draw out what is at stake to patients and their families when this is unsuccessful, as well as exemplifying positive impacts when systems of care work together successfully. In keeping with the phenomenological philosophy that underpins this study, the themes that are presented in chapters six to ten convey the 'essence of experience' of life as a family carer, throughout the illness trajectory. It is important to recognise that the findings presented here are the result of a co-construction between the stories told by participants in this study and the interpretation of the researcher (Gilgun 2005 in Creswell 2007, p. 179).

Extended quotes and case studies are provided throughout the findings chapters to illustrate the complexity of the issues experienced by participants, and to provide context. Presenting quotes in this way also offers the reader a deeper insight into the personal experiences of the carers in this study.

Chapter 6

Findings I: Roles & Relationships

As noted in chapter four, three themes emerged from the data. This chapter addresses the theme 'roles and relationships'. The chapter examines the role of family carers and particular aspects of the caring relationship; both with the person they are caring for as well as health and social care professionals. The chapter begins by considering how family carers make sense of their role; this provides a context to this chapter, as well as the rest of the thesis. The chapter then discusses carers' responsibilities, including practical aspects of care and the responsibilities associated with caring for a relative with a life limiting illness. The chapter also discusses carers' concerns regarding the blurred lines between expectations of formal and informal responsibilities for care.

6.1 Participants' understanding of their role

In many cases family members did not consider themselves to be 'carers', particularly in the early stages of their relative's illness. Many participants in this study understood their role as an extension of their existing familial relationship; as a person's spouse or daughter, for example, and suggested that they were simply supporting their family member through their illness. This finding supports that of others. For example, Ugalde, Krishnasamy and Schofield (2012) noted a lack of recognition of their role, with only two caregivers in their study describing themselves in this way. Many carers in the present study found it difficult to pinpoint when they began to consider themselves their relative's main carer. This recognition usually occurred later on in the illness trajectory and was associated with their relative becoming increasingly dependent and an increase in responsibility for their relative's day to day care.

Although this finding was not initially an objective of the study (and therefore is based largely on field notes), it is useful to include this insight here as it provides an important backdrop against which the rest of this chapter, and thesis, is set.

6.2 Carers' responsibilities for care

This section begins with a brief discussion of practical aspects of care, before moving on to explore the complexities of the lived experiences of family caregiver. The section aims to provide an insight into the changing role of carers throughout the illness trajectory.

6.2.1 Responsibility and decision making: blurred lines between family care and nursing care (as perceived by participants)

Family caregivers provide much more than practical support for the person they are caring for; carers are heavily involved in decision making and are, in many cases, responsible for the overall wellbeing of their family member. The sense of responsibility resounded across the sample, with many carers feeling a heavy sense of responsibility in their role. This is particularly the case in the home environment, as demonstrated below.

In the following extract, Elaine describes how her husband's health deteriorated over time and explained some of the difficulties she experienced in caring for him:

“And if [friend] hadn't put me on to this nurse I think he would have been at home til he died. Nobody was taking any notice... [clears throat], he might of hit me because he was, you know, he'd get annoyed because I couldn't take him home or get anythin. I let him out once or twice; he tried to go out and I wouldn't let him go out, cos he'd be so unsafe and- and, erm, I'd got my neighbours in once because he was so confused and agitated, and another time I sent for my daughter and her partner to come over to calm him down because he was talking all sorts of nonsense, like he had a house that he was selling and erm, he wanted to go and see it, so they took him for a walk up to the road in his wheelchair and cheered him up, and came back happy. So yes... he might of hit me, or I might of hit him [laughs]... which would have been worse cos you know, I should have had more patience but er, he went into hospital before either of us got too... too much [inaudible] with each other”. Elaine

The extract shows how Elaine, who was in her late seventies when caring for her husband, attempted to balance her and her husband's wish for him to remain at home with various difficulties associated with the progression of his Parkinson's disease. Elaine was the main carer for her husband during this pre-end of life stage and she drew on the support of her neighbours, friends and relatives. Her biggest worry was that her husband may hit out at her, or worse, that she may hit out at him in frustration. The involvement of a community neurological nurse helped to ease the situation and Elaine took the difficult decision to have her husband admitted into hospital whist they found a nursing home for him.

Feelings of responsibility and uncertainty particularly focused on medication. Joanna (who coincidentally is a qualified nurse) described an instance where her mother was experiencing pain at home towards the latter stages of her illness.

"I phoned up because mum was in pain, and they [district nurse] prescribed her medication over the phone, which was a morphine patch. Now to me, if somebody's in pain and you're prescribing morphine, as a nurse... they should have been seen, not go off what me as her carer had said to somebody. I didn't know whether she needed morphine, or whether she just needed some soluble aspirin or whatever. But they prescribed morphine for her. So we gave it to her". Joanna

Joanna was unsettled by the district nurse's decision to prescribe morphine without seeing her mother in person. This added to her worries and put her in a compromised position between acting as a family member and her role as a nurse.

Such feelings of responsibility were accepted as part of the role of being a family carer for many participants. However, others felt that the level of responsibility ascribed to them was more in line with a 'nursing role' with which they felt uncomfortable, and in many cases out of their depth.

Some participants felt that the level of responsibility encountered within aspects of their role at home was outside of their expertise, describing such responsibilities as akin to a 'nursing' role. This level of responsibility often required participants to make, what they felt, were clinical judgements about a person's condition; giving medication, monitoring pain, using equipment without proper training or tasks such as monitoring the colour and level of urine, checking wounds such as bed sores and giving injections. Carers worried that they were not 'qualified' to make such judgements and that this was really the responsibility of a health professional. The weight of this responsibility was a source of great worry and anxiety for carers in this study.

Janet particularly felt this way when caring for her father. Janet's father had a complex medication schedule, requiring him to take multiple medications at different times during the day. He was quite frail and had poor eye sight, therefore Janet took the responsibility of ensuring he took the right medications at the right times of day. She found this to be a difficult role in itself; a role that became increasingly difficult as his medications were frequently reviewed and then changed by doctors.

"I felt- especially the last two months, but actually the whole of the year before he died really, that role with his medicines it turned into a nursing role really, it really had." Janet

“Everyone’s very quick to say you know “You’re not a nurse”, you know, “this isn’t your role”, but actually it was my role at times, it was, with no training whatsoever; no briefing, no support. So it felt like a massive responsibility and what happened if I got it wrong? That’s what started to dawn on me; not only would he be hurt and heaven knows what complications it may cause and I don’t know how I would have lived with that, you know especially if it had caused a stroke or something, but would I have been in trouble with the Police? Could I have proved that I didn’t do it deliberately?” Janet

The second quote illustrates the weight of responsibility Janet felt she was dealing with and demonstrates the impact of this on her wellbeing. To put the quote in context, Janet felt that her role as her father’s carer was becoming increasingly demanding as his illness progressed. Her father was living in his own home at the time and she lived nearby with her two teenage daughters. Janet was a single mother and had little support from friends or family. The quote illustrates the level of responsibility Janet associated with her role, and the distress associated with the worry this responsibility caused her.

Janet was also required to make what she viewed as clinical judgements about her father’s bedsores in order to alert the district nurses if they became acute.

“I think er well certainly the bed sores at the end was an issue because I felt I was very much left to decide whether they were becoming acute or not acute.”

She continued:

“It put me in a position of having to look to see if those sores were becoming you know, more inflamed...or infected or so forth; I saw that as a nursing role.

[And] especially at the end, yeah, those last few months erm I used to do his blood pressure all the time because that told us about his heart. I mean in some ways I didn’t mind doing that you know because it gave me some information that allowed me to know about what was happening to him...

But again that would have been something in my mind that a nurse might have done.” Janet

In the above quote Janet indicates that taking her father’s blood pressure gave her an

indication of his health, which indicates that she did not feel that she had enough information on her father's condition from health professionals.

"I mean we always, I suppose like anyone really you've got to provide information about how far they can walk, and what his breathing was like actually describing it in great detail. At the end you're doing all sorts like measuring mucus, and er- you know, telling people the colour and measuring how much he drinks. Er measuring the urine output, er, which I was capable of doing, but I see those- once upon a time- I certainly can with my Grandma, District Nurses came and did things like that and I was doing it you know, erm.

[Pause]

Yeah, something else he got thrush on the inside of his mouth the last two months erm then that was probably that was maybe a nurse could have done that one but, that was quite unpleasant, but that was you know, we didn't care; we did it".

It is clear that some family carers were uncomfortable with particular aspects of care. This appears to be particularly apparent around duties with high responsibility or risk (such as medication, bed sores). It could be said that such aspects are actually unanticipated aspects of caring, with carers considering particular tasks to be something that community nursing staff should hold responsibility for. Furthermore, it could also be said that this places carers in a compromised and sometimes vulnerable position, as they do not feel equipped to make what they consider to be clinical judgements about their family member's condition. In this way, the roles and responsibilities of systems of formal and formal care are blurred in a way that clearly has a negative impact on family carers and the cared for person, as such aspects are a source of great anxiety.

6.2.2 The difficulties of personal care

Providing personal care such as washing and assisting a relative with the toilet is a particularly sensitive issue for both carers and patients. Understandably, issues around relationships and dignity are especially important and are very personal to an individual. In some cases patients feel that they do not want their family carer to assist them in this way; that it crosses the boundaries of what they find acceptable in a family relationship. In such cases, patients may prefer a formal carer to assist them. In other cases, patients do not want a formal caregiver, a 'stranger', to assist them and prefer their family member to assist them. Ultimately, this is a personal decision for a person with a life limiting illness to make. The

family carers in this study respected and supported the wishes of the person they were caring for, even though they too often found this issue difficult, as demonstrated by the following quote:

“And I did most of the personal care myself because that’s what [my husband] wanted.” Claire

The following extract from the interview with Jean further demonstrates the complexities around personal care. Jean worked part time and formal carers were arranged to come in to check on her mother whilst she was at work. Jean’s mother preferred Jean to assist with her personal care. The following extract demonstrates the difficulties that surround this and the sensitivity of the issue around dignity in care provision.

“and initially when [paid carer] started coming, [the] first couple of years my mum wouldn’t let her do anything, but I wasn’t bothered as long as someone was calling in on her and having a chat. I was happy with that because she wouldn’t let [paid carer] wash her [inaudible] because I used to do that when I come home...and that went on.” Jean

Jean revisited this issue later in her narrative, reiterating her mother’s views on personal care:

“It was only when my mum got sick.... the last time in the October that I said ‘Mum, please [formal carer]’s gonna have to learn....you’re gonna have to let [formal carer] shower you’ ‘cos she would never, ever let [formal carer] do it but by that point I was just so worn out; I was shaking. And me mum, she did. But you know, good enough, she started letting her do it but...and that took her knowing [the paid carer] for all them years of calling so you imagine a complete stranger [saying] ‘eh-are, we’ll give you a wash’...you know, and it’s different people every week; it’s embarrassing! It’s your dignity!” Jean

By contrast, Pat’s husband did not want for her to help with his personal care, but the practicalities of waiting for a district nurse to come often compromised his wishes. The following extract provides an insight into the difficulties that patients and carers face:

“In the day time, when it was just myself and my sister [in-law] here, if he needed changing, because he became doubly incontinent, erm...I dealt with that. I didn’t like doing it to be honest, but I did it because he was my husband and I loved him. But I found it difficult to do it on my own, and it

would take ages. It would take ages to do, and he would get upset because I was having to do it. So in the end, I would call the district nurses and they would come. But it could be like half an hour before they got here, which ok, doesn't seem like a long time to spend waiting, but when somebody's lying there and they need to be changed, you know, it's just the dignity of lying there". Pat

Furthermore, some family carers may find providing personal care very difficult. This maybe particularly so for male carers and for grown up children caring for their elderly parents. Barry, for example, helped to care for his mother who had ovarian cancer.

"Towards the end, my mum needed to be washed. I washed my mum, but I didn't wash any private parts. I'd wash her feet and she'd be sitting on the bed, like sitting down and I wouldn't look at anything, I'd just be cleaning my mum's legs and whatever." Barry

The issue of personal care transcends the home environment to the hospital environment, as the following quote demonstrates.

"Even when he was in the hospital I showered him [laughs] cos he hated anybody else doing it for him, you know what I'm saying? So I'd do it for him" Louise

In conclusion, issues around personal care are sensitive for both patients and carers. The findings suggest that carers put the wishes of their family member above their own on this matter. The issue of personal care is a key area that demonstrates how formal and informal systems of care work together to meet the wishes of the patient. A person's dignity is at stake when there are failures in meeting the needs and wishes of patients and the significance of this should not be underestimated.

6.3 Carers' expectations of the roles of others

Findings from this study indicate that some carers were confused about the roles of those involved in their relative's care. Both carers and patients had pre-existing expectations of roles of the health professionals involved in their care through the illness trajectory. The main area of uncertainty was the ambiguity between the role of a palliative care nurse (including Macmillan nurses and Marie Curie nurses) in the community and the role of district nurses, as the following quote demonstrates;

"The District Nurses came out and they said [that] they would be the ones who would care for [son]. Macmillan nurses only advise.... I don't know if

the hospital arranged it but they did say "someone would be out to see you". The District Nurses came out and they said, cos I thought Macmillan were the ones who dealt with cancer patients, but we were told everything had changed, er "The District Nurses will do the caring and the nurses, Macmillan nurses only advise". Carol

The findings suggest that family carers do not feel adequately informed about the roles of the various health professionals that will be involved in caring for the patient and supporting their caring role. This ambiguity led to some caregivers feeling unsupported and confused when a health/social care professionals' role was not what they anticipated.

Many family carers held the belief that Macmillan nurses provide hands on care for people with cancer, with some believing that this service provided 24 hour, one to one care. These carers were often disappointed and/or frustrated when the Macmillan nurse visited, often on a one-off visit, to advise on medication and/or offering emotional support.

Similarly, a number of carers explained that they were unclear why the Macmillan nurse had visited, as they did not attend to the patient in a way that they had expected. These carers thought that a palliative care nurse provided specialist hands on palliative care for the patient. My understanding of the data is that carers look for reassurance from palliative care nurse visits, as they have expectations of excellent care associated with experience and specialised training in terminal illness and end of life care. There is a distinct clinical expectation from carers, as well as the expectation that patients will receive the gold standard of care, tailored to their specific needs. However, rather than meeting this expectation, community palliative care nurses offer emotional support to patients and their families. This is in keeping with the ethos of palliative care; to look after the physical, emotional and spiritual wellbeing of patients and their families. However, the lack of 'hands on' care provided by specialist nurses was a source of confusion and frustration for some carers, as the following quote demonstrates:

"I said 'look, nobody's looking at his bottom' she'd say [palliative care nurse] 'Well I'll ring them [district nurses] and tell them' and I'm thinking 'well if you're a nurse, why don't you do that?'...so I'm not sure what role the palliative care nurse has in caring for a terminally ill patient, apart from saying 'are you alright?'.

I mean she would talk to me and say 'are you alright?' and I mean, you get upset occasionally ...but I can't see what....what benefit there was in having a palliative care nurse.

I don't mean to be critical, because I know other people have fabulous experiences...but I just could not see where she fitted in to the circle, and the circle was definitely not joined up at all; it was confusing and I felt that the district nurses resented the palliative care nurse because she would ring them and tell them what to do". Linda

Such comments provide further insights to our understanding of the experience for some caregivers. Firstly, it suggests that carers put the patient's care and wellbeing above all else. Secondly, that some carers may struggle to recognise the support that is being offered to them in this implicit manner. Thirdly, that carers feel a great deal of uncertainty in care provision and lastly, there is a suggestion some that carers may feel 'stuck in the middle' in the co-ordination of care. Family carers may also recognise political or other tensions between health professionals.

Linda went on to say:

"Between September and just before he died I think she [Mcmillan nurse] visited the home maybe four times. She would ring up on a Monday 'do you need a visit?' and I'm thinking well 'what d'you do when you come here?' um....you just sit by the bed and say 'anything worrying you?' erm, or she'd say to me 'how are you coping?' so in the end I just said 'no I'm fine. I'm coping'. Now I could have been at fault there, er, I don't know but I really don't know what her role was.

There were times where um....he's on potassium 'cause he had very low potassium level and that can affect the heart and uh.... I was thinking does he need to up his potassium or do we need a blood test or you know is the blood test worth it because he's a dying man, you know, 'well ring your GP'....what's she [Mcmillan nurse] coming for then? you know, it was fine really uh....and I think.... I would have been better with just the district nurses erm rather than the Macmillan nurse because I really, really don't know what the role was". Linda

Other expectations common in the data concerned practical aspects of care regarding the district nurses' role. There was also particular concern regarding pressure sores, as it was very difficult for carers to find the 'right' person to assess and attend to them, as Linda found *"I said 'look, nobody's looking at his bottom' she'd say [palliative care nurse] well I'll ring them [district nurses] and tell them and I'm thinking 'well if you're a nurse, why don't you do that?'. Additionally, some carers held the expectation that night care would be available at the end*

of life and that a healthcare professional may be present to provide support and reassurance in the time approaching a person's death. Such services do exist but are very limited.

These findings support those reported by Denham et al (2006), who reported that patients and family members often have difficulty distinguishing between the roles of community healthcare professionals, giving the example that formal caregivers are often mistaken for having medical knowledge, such as that of a nurse. This may place unrealistic expectations on formal caregivers and cause further confusion around role ambiguity (Devlin & McIlfratrick 2010; Herber & Johnston 2012). Furthermore, Ferguson et al. (1998) note that the roles of informal and formal care are not black and white. Their research identified that Macmillan carers worked at the 'intersection' of formal and informal care and that this had 'considerable implications for their daily practice' (Ferguson et al. 1998, pp. 7, 12).

It is clear that confusion surrounding the roles and responsibilities of health professionals in community care is a cause for concern for family carers. It is a recommendation that the roles of professionals involved in the care and support of patients and their families should be clarified as soon as possible in order to minimise anxiety, manage expectations, enable carers to feel that they are getting the right support from the right professionals and to improve satisfaction with these services.

6.4 Carers as experts in person-centred care

A person may be considered an 'expert' when they have breadth and depth of knowledge on a specific topic, or, as the English Dictionary and Thesaurus (2000) defines an 'expert' as "a person who has extensive skill or knowledge in a particular field". This definition of an 'expert' may be applied to family carers when we consider that, over time, family carers develop a specialised knowledge about person they are caring for and that person's wellbeing; their personality, their needs and wishes, their physical and mental capabilities and limitations, their reaction to symptoms such as discomfort or pain for example. This puts family carers in a unique position in terms of the quality of personalised care they can give the person they are caring for. Additionally, family carers may spend more than 50 hours per week in a caregiving role (Department of Health 2012a); allowing them to provide quality and personalised care to family members.

The notion of 'carers as experts' first gained attention in the academic literature in the 1990s. The relevance of this notion remains important and emerged as an important issue in data in this study. Nolan, Grant and Keady (1996) proposed a 'carers as experts' model, which is based on the partnership between systems of formal and informal care and which recognises the likely change over time in a carers expertise and the subsequent changing balance

between power and expert knowledge at different points in the illness trajectory (Nolan 2001; Nolan, Grant & Keady 1996).

Thorne, Ternulf Nyhlin and Paterson (2000) argue that traditional notions of health care relationships exist in health care environments. These notions are that the paid professional is the expert in care; that the paid professional acts as the gatekeeper to other health care services; and that patients are 'good' patients and are compliant (Nolan et al. 2003, p. 6; Thorne, Ternulf Nyhlin & Paterson 2000, p. 303).

In the home setting therefore, it could be said that carers are the experts in terms of looking after many aspects of their relative's care. This however can change significantly if the place of care shifts to an acute setting. Some family carers felt that they became disempowered in a hospital environment. In such circumstances some carers in this study felt that they were put on the back seat and their opinion was rarely heard. This finding supports those of Lowson et al. (2012), who use an orchestral analogy to illustrate how a family carer may go from the 'conductor' of an orchestra to playing 'second fiddle' to describe this phenomenon.

The following quote from Janet provides an example from the present study that supports Lowson et al's (2012) findings. This example demonstrates that, in a hospital setting, health professionals may focus exclusively on the patient and exclude family caregivers. In some cases this leads to caregivers feeling devalued and disempowered:

"Whenever he was taken into hospital erm you know I wasn't allowed to stay by him you know, I was always sent away from where he was if the Doctor was around or a nurse was around, and it was only at the very end erm I started to challenge that and say- obviously I asked my Dad first and he would say "I want you to [stay]".

And it depended then, it was absolutely selective as to who would let me stay and who wouldn't, some would just say "no you can't, you'd just have to go out there", and actually I felt that was - there was something about that that left me feeling disregarded because I was good enough to be there for however many hours every single day doing all the tasks, but I couldn't hear what was being said even though my Dad had given permission... I think that left me feeling like, 'well yeah, you're a carer but... so what?'

...It seemed like when there was a carer with a patient and the carer had a uniform on from a nursing home, that carer seemed to be more privy to information than I was." Janet

Such behaviour may be attributed to patient confidentiality; however, Janet explains that her father had expressed his permission for his daughter to be privy to information about his condition and his care. Recommendations from Australia suggest that patients and carers be treated as a 'unit of care' by health and social care professionals (Palliative Care Australia, cited in Hudson 2005, p. 78). The above example provides evidence to support this recommendation, as Janet's experience was clearly a source of distress and led to her feeling '*devalued*' and '*disregarded*' as a carer. This is perhaps particularly poignant for Janet, who described feeling overwhelmed by the responsibility of the practical aspects of caring for her father at home. For Janet, the difference between her responsibilities for her father's care at home, where she was the 'expert' in his care is in stark contrast to how she was treated in hospital. Janet often felt overwhelmed by the weight of responsibilities when caring for her father at home, but was not able to get any help. By contrast, in the hospital environment she felt pushed aside and was not able to obtain any information about her father's condition or care. My interpretation of this is that this stark contrast served to illuminate her role as her father's 'carer' in different care environments (this will be discussed further in chapter 7). Furthermore, Janet's observation that formal carers were '*privy to more information than I was*' adds to her frustration and feelings of being '*disregarded*' and further illuminated her role as a 'family carer' in the wider realm of health and social care. This again highlights the issue of carers being the 'expert' at home, but appear to have a devalued status in hospital environments.

Carers may also draw on their 'expert' knowledge of their relative to raise issues of concern with their relative's GP. There were numerous instances in the data where family carers raised issues of concern with their relative's GP. They described that these concerns were glossed over by clinicians, only to later find out that their concerns were valid and significant. Such circumstances led to carers feeling undervalued and that their opinion did not matter. They also led some carers to question the competency of health professionals, as the following quote demonstrates:

"and it took people ages really to answer my concern; something's really wrong, you know? It was just... and at that point it was like as if they could hear me and then took notice to him and we were rushed into a Doctor and at that point I said "we can't bring him anymore, we won't do this anymore". But that was about six weeks before he died, which, yeah, so the validation for carers is you know, it's quite horrible at times...Quite... disrespectful and dismissive, especially you know at that stage for me I'd been caring for twelve years; it was my job and that was hard to bear really. And my Dad was entrusting me with his life". Janet

As Janet suggests, being a family carer is a position of great responsibility; carers often act as advocates for their relative if they notice a change in their health and wellbeing and raise it with a health professional. The above example demonstrates circumstances where a family carer may possess 'expert' knowledge about their relative's health and wellbeing, but have difficulty in having their voice 'heard'. As Janet explained, her concerns were ignored for a period of time and only listened to when a crisis occurred. In the above quote Janet asserts that she cared for her father for twelve years and considered it to be her 'job'. This adds strength to the argument that carers may be considered as 'experts', as well as adding to our understanding of carers' perception of their role.

Developing on this point, Catherine presented herself as an 'expert' to a hospital steering group:

"There are so many things that are er- you would want to do and I did and yet the attitude towards you doing it was, you know, this one, you know was "I'm the professional erm, and and who are you?" "Well I'm the [carer]"- I remember sitting in a meeting er, the first meeting I ever went to at the hospital of the Cancer Care Group, and the general invite [introduction] was to "well we've got quite a number of professionals here today from different disciplines and erm, and are pleased to welcome er a member of the public, er [Catherine] who is here as a carer", and I said "Er, I'm the professional"...because they don't give carers credit for actually being the professional when it comes to caring for er their loved ones". Catherine

This demonstrates the strength of feeling around this issue; that family carers feel that they have an important voice and should receive a higher status than that they currently receive. It also suggests that an interesting power dynamic is at play between family carers and health professionals; that carers are the experts at home and are supported by community teams, but that if a person is admitted to hospital then family carers lose their status and may come to feel disempowered.

Indeed, over time many carers develop an in-depth knowledge of a person's condition. In some cases this knowledge may exceed that of the nursing staff caring for the person in hospital. This is not altogether surprising when considering the vast range of common and less common health conditions. With this in mind, there are likely to be cases where a person being cared for in hospital may have an uncommon condition; in cases such as this 'carers as experts' gains a further dimension. Sharon's husband suffered from Progressive

Supranuclear Palsy (PSP)³³ and was admitted to hospital on several occasions during his illness. Sharon explained that her husband had received particularly poor care in hospital on one occasion. She felt that the staff looking after him did not know enough about the illness or how it affected her husband in terms of his limitations and capabilities. In order to raise awareness of this condition amongst the hospital staff (and also raise standards of care for other people with this condition) Sharon obtained printed cards from a charity to hand out to hospital staff:

“He went into hospital- well he went a few times because he fell and he [inaudible] and er...they don’t know enough about the illness; they don’t know. I used to carry a little card around with me, or cards, that I used to just go around and give them and say ‘This is what he’s got and this is how he is’... And I used to find that the best thing because they [nursing and support staff] used to read it and then realise what was going on. Because otherwise you’re just a number in the hospital and they- they haven’t got a clue how to treat them.

I mean he went [into hospital] one time...and I’d said to the doctor ‘He has to have somebody to go to the toilet with him. He has to have his pad changed, you know, he can’t do it himself’ and I went and picked him up at lunch time the next day and he was sat in the chair absolutely sodden from top to bottom. They hadn’t even changed him. And I said ‘Did you say anything?’ and he said ‘Yes’ but he said ‘She said here’s the pad, get on with it’.

But I think hospitals- I know they get an awful lot of illnesses and things going through the system and they can’t know everything and this is why I used to take the card along with me and say ‘This is what he’s got’ and I used to give it to them, and they used to put it on his file. And a lot of people were quite interested actually.” Sharon

This extract demonstrates how expert knowledge from informal systems of care, in this case a charity and family caregiver, interact and support formal systems of care to deliver improved care and support in the hospital setting. The above example also illustrates what may be at stake when there is a failure (in this case, inappropriate and substandard care) and demonstrated that patient care may be improved when formal and informal systems of care work together.

³³ A neurological condition

Expanding on the idea of formal and informal 'experts' in care, a number of carers felt that the level of care in hospital was inferior to that that they were providing at home. This was particularly the case with hygiene and personal care and also in relation to bedsores, as demonstrated by the following quotes:

"Now [husband] had erm a bed sore which was four out of five³⁴, he developed it in [name of hospital] and that was one of the things they returned him to me with and a very, very bad bed sore at the base of his spine. Erm, and er, and he'd never had a bed sore in all the years that I'd been looking after him." Catherine

"[my husband] had some scratch marks on his bottom one day and they [hospital staff] said "Oh, he scratched it"... so I said "Well if it's not treated today it will break down". "Oh, it'll be alright". Well next day it broke down...into a pressure sore". Claire

Examples such as these suggest that carers often feel that they provide 'expert' care at home, but that the quality of care is compromised when the cared for person is in the care of the hospital. Many patients and carers in this study sadly had negative experiences of hospital care, which impacted on their willingness to relinquish responsibility to the hospital staff. This wariness may have developed from previous experiences of poor care, or from the carer feeling that they were indeed the expert in caring for their family member, as Catherine demonstrates:

"I came in one day at two [o'clock] and I noticed his sheets were wet erm, and er I asked for the nurse to be called and I then went back in, er pulled the sheet aside and noticed on the sheet there was a little pool of what appeared to be mucus with black spots in it.. so erm, I went out again and I said "could you call a nurse right away I er I need to show her something". So a nurse came in and er I said, "I don't know what that pool of mucus is there and I'd like a Doctor to come and er see it". So she said erm, "Mrs S that's come out of [husband's] bed sore and I said "I can't understand, I've never seen anything like this come out of his bed sore" and if I'd thought about it quickly enough anyway at the time I would have said "his bed sore is packed so could it come out?"

Erm, but I wasn't thinking but I just knew that that hadn't come out of his bed sore, so erm the .. and then the auxiliary or whatever support person

³⁴ A rating scale for bedsores that indicates their severity.

said, "Oh yes, Mrs.. I've seen this type of thing before come out of a bed sore". Erm, and I said "I want a Doctor, that has not come out of his bed sore". And the nurse said, "A doctor is not going to tell you anymore than I've already told you Mrs_". So, just at that moment my wonderful [husband] passed a little, passed a little bit of wind and out popped the mucus, I think it had come out of his anal passage.

So I just turned on her and said "right you get me a Doctor immediately, I want this investigated"... And when a Doctor arrived she took one look at it and she said "it's inflammation of the bowel erm, but we need to get it investigated". Erm, so that's when of course he was erm, it was investigated, and that's when they discovered he had a bowel cancer."
Catherine

Further analysis of Catherine's transcript helped to interpret that this experience made Catherine question the competency of the staff caring for her husband in hospital. The impact of this was that she then felt that she had to be there as much as possible to ensure that her husband was looked after adequately. Following this event Catherine lost trust in the nursing staff attending to her husband. Catherine found this event particularly distressing as it occurred in the last days of her husband's life.

Carers may also be experts in using specialist equipment when caring for a relative. Occasionally a person's care was compromised when the staff, whether in the hospital or formal carers at home did not have specialist knowledge and had not received the training to use the equipment. In a number of cases family carers trained health and social care professionals to use the equipment, however, a number of difficulties transpired in such circumstances. One to one training requires time and works on the premise that the same individual(s) will continue to care for their relative. This study found that a lack of continuity of care was a major issue for participants (this will be explored in more detail in the following findings chapters). This leads us to consider the possible quality of care and impact on both carer and patient in cases where a vast number of health and social care professionals and/or formal caregivers visit patients at home or care for them in hospital or nursing homes. Jean describes her experience in the quote below:

"I trusted nobody; I'll be honest with you, with her...

The inhalers, you know she had to be reminded to use the inhalers....but no, they didn't know what to expect and when she come home they also gave me um....I don't know what it's called... and they didn't have a clue

about it.....they didn't have a clue about nothing. I had to teach [formal carer] what to do." Jean

6.5 Summary

In summary, informal care provided by family carers offers unique personal insights into the needs, wishes and capabilities of the person being cared for. Family carers develop an expert sense of a person's mental and physical wellbeing, which helps carers to interpret situations or to make decisions on their relative's behalf and in their best interests as their health declines. Despite having 'expert' knowledge on a personal level, carers have limited knowledge of clinical issues and find it difficult to make clinical judgements in the home environment. Conversely, health professions such as those in the community or in hospitals have limited personal knowledge of the person as an individual, but (in the vast majority of cases) have expert clinical knowledge. Improved interaction between informal and formal carers, across all care environments, may offer the possibility to combine different aspects of expert knowledge and result in the best possible care for patients.

Chapter 7

Roles & Relationships Part II: roles & place of care

Having examined the roles and relationships of family carers in Part I, Part II examines the dynamics of formal and informal care and the caring relationship in different care settings. The chapter presents models of care to demonstrate how carers and patients are supported by both formal and informal systems of care at home, in hospital and in a hospice.

Many people with a life limiting illness are cared for at home, for part, or all of their illness. Others may experience home care, followed by a temporary or long term stay in a hospital, hospice or a nursing home. A key strength of this study is that the retrospective narratives of bereaved family caregivers provide a valuable insight into the transitions between different places of care throughout the illness trajectory.

This chapter aims to illuminate the dynamics between formal and informal care that operate when caring for a person with a life limiting illness. Models are used to illustrate these dynamics and focus on how the dynamics of care change in different places of care. Carers' experiences of this shift are also discussed in this chapter.

This chapter attends to the research question by examining the interactions between formal and informal systems of care across different places of care that people may experience during the illness trajectory.

7.1 Introduction to the model

Blair (2012) draws upon models of dyadic and triadic care to demonstrate the dynamics of caring relationships (Figure 10). The dyadic model depicts a two way relationship between the healthcare professional and the patient. By contrast, the triadic relationship model recognises the role of the patient's family and incorporates this into the model.

Models of dyadic and triadic care are useful, as they allow us to understand the principle of relationships between formal and informal care. They are however, rather rudimentary, as they lack detail about the dynamics, interactions, roles and relationships between health care professionals, informal (family) care and formal (paid) carers. Furthermore, they shed little light on how care relationships vary in different care settings, such as home, hospital, hospices or nursing homes.

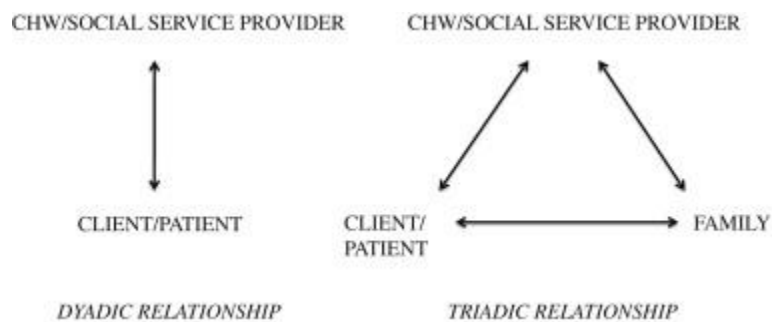


Figure 10: dyadic and triadic care relationships³⁵ (Blair 2012, p. 1774)

The data gathered for this study demonstrates the complex, dynamic and changing nature of the caring relationship over time and in different places of care. The models presented in this chapter were developed by the researcher in an attempt to capture this and demonstrate this complexity in more detail. The models are therefore rooted in the data.

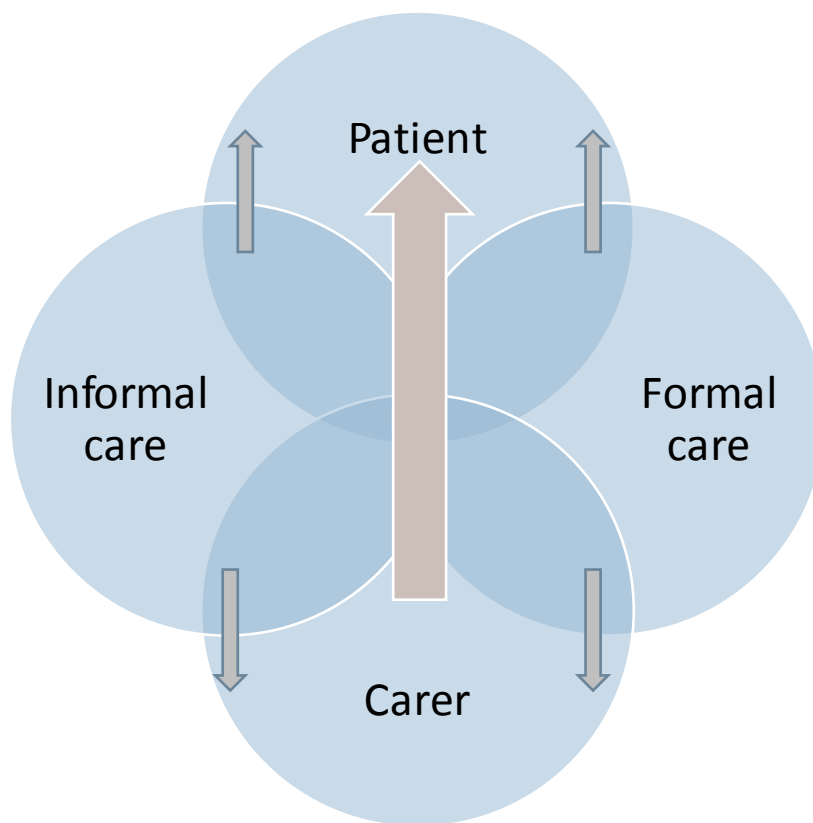


Figure 11: Model of care proposed in this thesis³⁶

³⁵ chw: community healthcare worker

³⁶ Arrows indicate formal care or support, whilst overlapping of circles represents the interaction between systems of care

The arrows in each of the models demonstrate the direction and weight of responsibility of care and support between patients, family carers, formal care and other informal care. Furthermore, in addition to the dyadic and triadic models shown in Figure 10, this model (Figure 11) shows how the main caregiver is also supported by informal and formal systems of care. In the following sections, this generic model will be amended to reflect the dynamics of care in different care settings and will be supported by exemplars from the data.

7.2 The dynamics of care at home

Sharon's experience provides a useful exemplar of formal and informal care working together to support both the carer and the person being cared for.

Sharon cared for her husband, who had been diagnosed with Progressive Supranuclear Palsy (PSP, a neurological condition). She cared for her husband at home and was both practically and emotionally supported by their family and friends. She also received support from various formal agencies. The following quote demonstrates how Sharon and her family adapted to helping to care for her husband.

"...then I started having carers coming three times a day. I cut down my work to three times a week so that I could look after him. I had no [formal] carers at weekends at all. As a family we did it ourselves. He's got- well he did have three children, you know, erm, which was great cos they're nearby. Erm, and then erm he was fine while we were here and then and up to last Christmas he was quite good, erm, mind you, we were all feeding him; he couldn't hold a spoon or anything, we had to feed him everything". Sharon

Sharon worked for the city council and, as such, she felt that she had a good knowledge of the services available to support caring for a family member at home and also how to access them. As well as a supportive family actively helping to care for her husband, Sharon also had support from various formal agencies throughout the illness trajectory; district nurses visited twice a day and formal carers visited three times a day. They were also supported by a specialist nurse, who had expert knowledge and skills in neurological conditions. Sharon and her family also had support from night carers for the last two weeks of her husband's life.

Sharon's case demonstrates the positive impact that having support from both formal and informal systems of care can have. It is an example of how caring for a loved one at home is an important and rewarding experience; one where the carer feels supported and reassured.

When Sharon's husband died, she and her daughter washed him together. Sharon felt comfortable with this as her daughter had prior experience of this from her work as a carer in a residential home.

Sharon also felt that caring for her husband through till his death also helped her through her grieving;

"Some people can't, and I understand that. Erm ,it's just how you are I think erm and if you can do it, I think you should do it really, erm because it does help. Erm, it helps I think in the grieving situation as well; I'm still grieving, but not as bad because I've done it and I know that we did as much as we could for him. Erm and everybody else helped by doing their bit, so that was good really."

Sharon

Having help 'from everyone else' enabled Sharon to care for her husband at home until his death. Although this may not be possible in all situations, this case emphasises the importance of informal and formal care working together. In terms of the research question, it is insightful that Sharon links being able to care for her husband at home until his death with helping her with her grief. This suggests that had formal and informal care not successfully worked together, enabling her husband to die at home, then this would have negatively attributed her grief. It is plausible then to consider that a person's grief may be positively or negatively impacted by the success of formal and informal care working together in achieving a shared goal.

Sharon's case provides an example of what may be considered as good practice for care at home. However, this positive experience of caring for a family member at home was an exception within the study. For Sharon, service provision, funding, and communication between formal agencies came together successfully, providing adequate care and support for families caring for ill relatives at home. However, Sharon recognised that her employment at the local city council provided her with an insight into the care system, such as what services were available and how to access them. This 'insider' knowledge is likely to have contributed to the stream-lined service provision which resulted in her positive caring experience. By contrast, the majority of participants in this study did not feel adequately supported in caring for a family member at home.

Many carers in this study expressed feeling exhausted and unable to cope. This was frequently compounded by a lack of sleep, as carers often experience disturbed sleep and/or stay up during the night to attend to their relative. This resulted in many carers feeling overwhelmed and unable to cope or function properly. After a long journey of caring, with

ever increasing responsibility, many carers explained how difficult they found maintaining their role and their caring responsibilities 24 hours a day, particularly at the end-of-life.

The following quote demonstrates this point; Joanna felt completely overwhelmed caring for her husband at home. She was supported by her family, friends and formal systems of care:

“I can’t describe it – I kept a diary to help myself, [to] stop myself going insane in those eight months and I actually wrote on the front of the diary, “I feel like I’m on an escalator going down into hell.” Because that was how I felt” Pauline

End-of-life is a very important and often very difficult time. Participants in this study felt that this time should be a special time to spend with the person they love; that it should be as peaceful and stress free as possible. Rather, the days and weeks preceding a person’s death was often very difficult for families, and was often compounded by a lack of sleep.

Night support is often provided through social services, through a ‘care package’ or, in some areas of the UK, through specialist Macmillan nurses (Clark, Ferguson & Nelson 2000) or Marie Curie nurses. Funding in this area is extremely limited, yet it is invaluable to families who are supported in this way. The impact of the presence and absence of night support will be discussed further in the subsequent results chapters.

It is important to acknowledge that having a family member become seriously or terminally ill is inevitably likely to be stressful and difficult time for a family. However, the majority of participants in this study reported difficulties which exasperated this event. The majority of participants in this study portrayed negative experiences. Communication between services was often poor and formal care often sparse, disjointed and, for many, often came too late. These factors contributed to a stressful caring experience and compromises the quality of life of both the patient and indeed the carer. Sharon’s knowledge of the local services no doubt contributed to what she considered to be a positive caring experience and enabled her husband to have a ‘good death’ (Smith 2000; Steinhauer et al. 2000). Transparency regarding the availability of support and service provision and fundamentally how to access this, is paramount to improving the quality of life of carers and patients.

Rather than possessing ‘insider’ knowledge, there should be a seamless co-ordination of services, with responsibility of this co-ordination lying with formal systems of care. But as Lowson et al. (2012) have demonstrated, carers are central to the streamlining of services and as such it is paramount that they have information about services available and how to access them at their fingertips. Carers should be provided with greater knowledge and of

services, which would empower them to access the care and support they need, at the time it is needed.

Developing on the ideas presented by Lowson et al. (2012), the findings of this study suggest that carers are often the coordinators of care at home. Many carers in this study explained how there was poor communication between different teams of formal support, which resulted in the carer effectively becoming the co-ordinator between services.

Figure 12 illustrates the emergent picture of home based care for people with a life-limiting illness and their family carers. In this model, a family member acts as their relative's main carer, with the carer and patient receiving some degree of support from both formal and informal systems of care. This model is set within the context of the findings and discussion presented in this thesis.

Having trust in health and social care professionals was an important factor for family carers. The following example demonstrates this in the home setting.

"We felt that we could trust them [community matron] with mum and I think that's a big thing as well, you've got to...as a family member, be able to trust the person you love into somebody else's' hands, cause it's not you doing it." Joanna

The findings presented so far largely suggest that carers would welcome additional support from health and social care professionals. However, Diane's narrative challenges this as a universal assumption and demonstrates how aspects of care may hold different meanings to different individuals. Although there were some cases of the *patient* refusing additional support from formal systems of care, Diane presented an interesting case, as she refused additional support as she felt it was personally important to her to care for her husband herself. This was possible as she was a retired nurse. This case however challenges the assumption that all carers want additional support.

The findings presented here suggest that access to and quality of support through formal and informal systems of care at home impact on the quality of life of both patient and carer. Figure 12 attempts to depict the dynamics of home based care. In this model, both carer and patient receive support from both formal and informal systems of care, but the majority of care is undertaken by one family member.

It is useful to consider this model in relation to both Sharon and Pauline's experiences. Whilst the model demonstrates the direction of support and responsibility of care is comparable in

both cases, the above quotes demonstrate that the *experience* of being supported in this way can be very different.

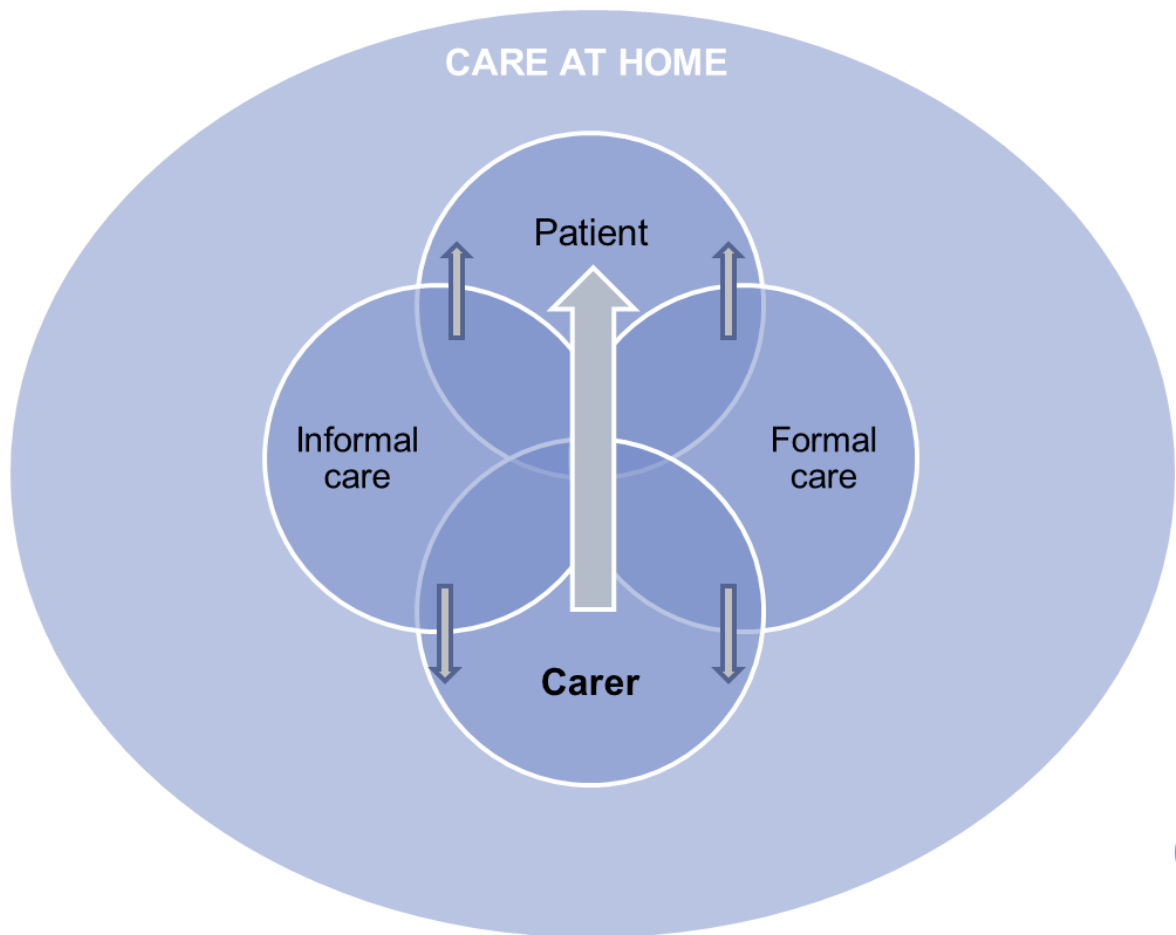


Figure 12: The interaction between formal and informal care at home

7.3 Hospital

Many people with life-limiting or terminal illnesses spend periods of time in hospital; this may be a temporary admittance before being discharged home or to a hospice or a nursing home, whilst others may die in hospital. For many, the move from home to hospital involves a shift in the primary responsibility of care from informal to formal systems of care, where family members traditionally play a *supportive* rather than *active* role in care. Furthermore, other friends and family may provide a supportive role in the care of the patient or supporting the carer at home. Figure 13 provides a visual representation of the direction and responsibility of care and support for patients and carers in the hospital environment (indicated by the direction and size of arrows). This model depicts that the patient is still supported by the main

caregiver and (often) other friends and family, that the main responsibility for care is provided by healthcare professionals (formal care).

The narratives from participants in this study suggest that the shift from the dynamics of care at home to hospital based care was often a difficult and complex negotiation. This will be discussed further, drawing on quotes from participants to illuminate the *experience* of care in a hospital setting.

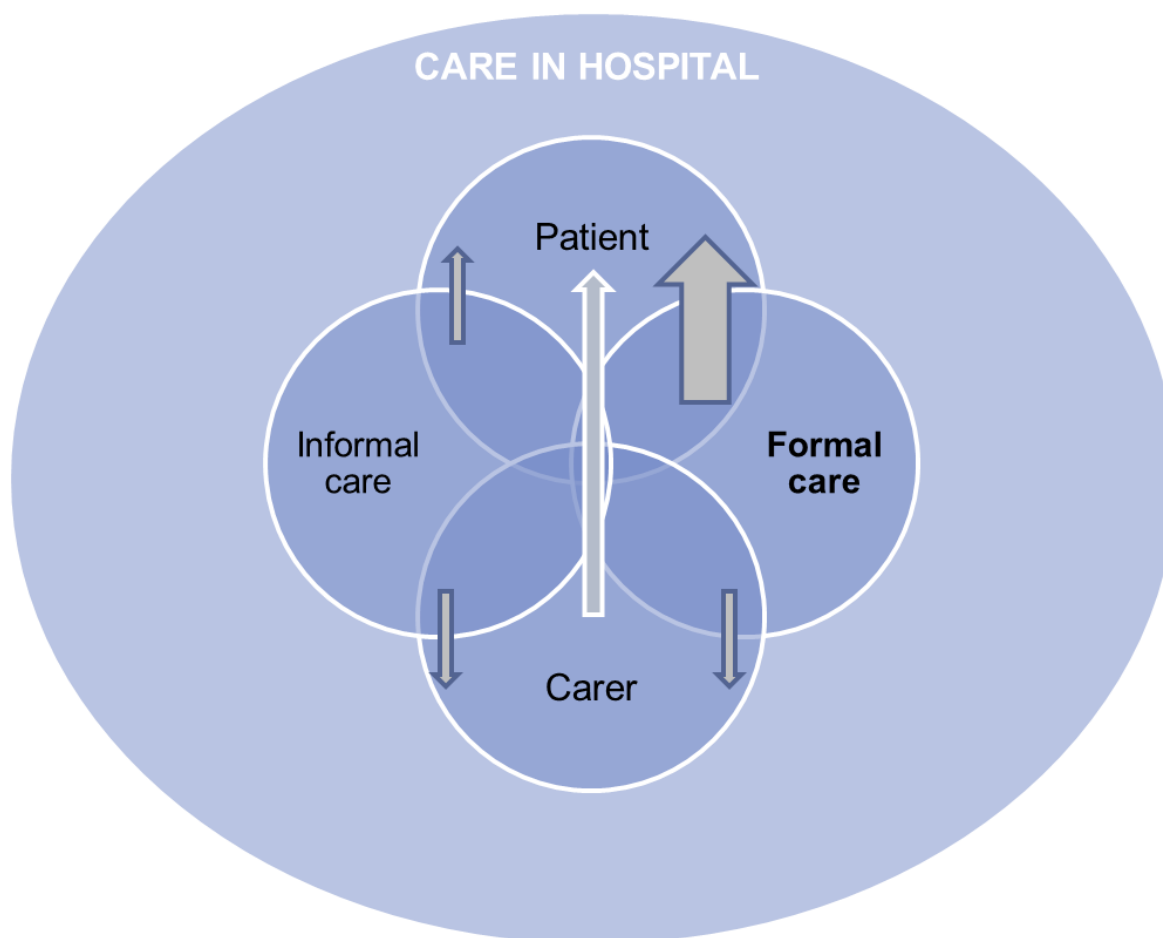


Figure 13: The interaction between formal and informal care in hospital

Despite the difficulties that many carers faced in caring for their relative at home, family carers endeavoured to ensure that the person they cared for received the best possible care; care that is person centred, timely, personal, based on a close family relationship and is multi-dimensional, in terms of not only the person's physical needs, but also their emotional and personal wellbeing. Although there were some examples of good care in the hospital environment, hospital care was a negative experience for many. Many carers, and indeed patients, felt that the care was inadequate because in many cases it could not meet a

standard that was seen as acceptable. In such instances, family carers therefore felt that they should be present as much as possible in order to act as an advocate for their relative and to ensure that they received (what they considered to be) an acceptable standard of care. This can be demonstrated in the following quote from Jean:

“I think too much paperwork takes time away from care...cos you know, a nurse is trying to speak to someone and the buzzers [are] going off and everybody wants the commode, and then the patients; they’re wetting themselves or they’re getting angry or they’re getting upset and....it was just horrible to watch...and as I say, thankfully my mum had me and....and I....I feel sick at the thought of if I hadn’t been [there].” Jean

Jean felt that it was important that her mother was able to maintain as much independence as possible during her time in hospital. This included an expectation that she be helped to the toilet in reasonable time, for example. The above quote gives a sense of the busyness, even chaos, of the ward environment in which her mother was being cared for. It is important to note that Jean does not criticise the competency of the hospital staff, but notes that ‘too much paperwork takes time away from care’. This kind of empathy and understanding with the nursing staff is representative of the views of many of the participants in this study; family members frequently recognised that wards were short staffed and were aware of the pressures on the nursing staff. This is an interesting dynamic in terms of the interactions between formal and informal care, as although this did not legitimise poor care, there was a degree of empathy and understanding for the nurses’ situation. This issue was recently raised by the Royal College of Nursing (RCN), who surveyed 6,387 of its members practising in the NHS between March and April 2013 (Royal College of Nursing 2013). The RCN acknowledged that ‘non-essential’ paperwork and admin equated to 2.5 million hours of nursing time each week in the NHS and called for this issue to be addressed (ibid).

The following quotes from Catherine further demonstrate that carers’ feel it necessary to be present as much as possible to ensure an adequate level of care.

“I always insisted on staying on the ward erm, you know, during the protected mealtimes because it was the only way- I had no trust, it was the only way I could ensure that he got food and was erm, er given enough fluid. So, as soon as visiting was an hour from 2 [o’clock], I just stayed right through ‘til 8 o’clock.”

"Part of it was wanting to be there, but part of it was also not trusting the hospital to take care of him. But er, that was the biggest thing as well, I, I, truly could not trust them er to take care of him. I suppose this is all to do with tied up with being a carer; I mean you're the one who has looked after your husband, your wife for many many years, always been there for them. Yes, you've had support during that time but at the end of the day it's down to you and er, erm, and to- in a way pass him over to somebody else er when your experience of passing him over has been a bad experience, you know, like dehydrating him, erm before and erm, er, as I say on two occasions finding him lying in his erm, you know, diarrhoea and not giving him his medication and so on and so forth erm, you just, you just don't- your trust has gone, your trust has gone." Catherine

Several experiences of poor care led Catherine to feel that she needed to stay with her husband at all times because she felt that the care was inadequate. She offers an important insight into her feelings about caring for her husband; that she cared for him well at home for many years and felt responsible to ensure that he continued to receive an acceptable level of care in hospital.

In 2011 the Royal College of Nursing proposed that family carers take on a more formal role in care in a hospital setting. Dr Peter Carter, Chief Executive and General Secretary of the Royal College of Nursing stated:

"We know that there are real benefits for patients where relatives can get involved in care, if that is what both the patient and family want. We would never suggest that relatives perform tasks that nurses are trained and paid to do, or that they should be compelled to carry out any task. However, we know from areas such as children's care that having familiar people involved at mealtimes for example can make hospital stays in particular less stressful for all concerned. What we would like to see is flexibility to allow relatives to help make patients comfortable." (Carter 2011).

To date, no further comments or details have been made. It is interesting to consider Peter Carter's comments in relation to the quotes and experiences of the participants in this study, as the ideology behind this quote appears to be very different to the practice that is taking place. Mr Carter describes family members' involvement in caring for their relative in hospital as gently enhancing patient care, yet carers' experiences of being present in hospital are about necessity and a lack of trust in healthcare professionals to provide an adequate standard of care should they not be present.

Carers' experiences of end-of-life care in hospital were often more positive than carers' experiences of pre-end of life care. In many cases patients were provided with their own room in a side ward and policies on visiting hours were relaxed or were unrestricted. Specialist palliative care teams may also become involved in the person's care (Higginson et al. 2002). Other evidence from the data suggests that end of life care in hospital can be variable. There may be no additional support from a specialist palliative care team in delivering end-of-life care to the patient. Alternatively, there may be the involvement of the palliative care team on a general ward or in a side ward, or the patient may be moved to a specific palliative care ward, which may be considered as more of a 'hospice' environment with its own ward culture.

Carers who had supported their relative in the hospital environment during pre-end of life care sometimes found the thought of hospital care at the end-of-life distressing and in some cases they made express wishes that hospitals would not be the chosen place of death. Indeed, the majority of people (60-67%), presented with the right circumstances, would elect to die at home. Yet, in 2010, 53% of people died in hospital (Gomes, Calanzani & Higginson 2011). Poor pre-end of life care was a great source of stress to families and therefore may impact on important decision making around their relative's preferred place of death.

Findings from this study suggest that there is little emotional support for patients and family carers in hospital settings. However, kindness, compassion and empathy emerged as being particularly important characteristics, but this varied widely and was very much dependent on individual personalities or the culture of a team. In contrast, palliative care teams within hospitals appear to successfully develop relationships with the patient and their family, provide excellent care, have good communication with the family and do so with the kindness and compassion needed at end-of-life.

Negotiating one's role within a hospital environment can be complex. As the Royal College of Nursing (RCN) suggests, family members may, in the future, be more formally involved in caring for their family member in hospital. However, until this discussion is addressed more formally, it could be argued that hospital staff hold the main responsibility for care and remain the 'experts', at least in a clinical capacity, in a hospital environment. Perhaps in the future carers and patients will be treated as a partnership or a team by health professionals in hospitals and a true model of triadic care will unfold.

Although there were many instances of good care in hospitals, there were equally many instances of poor care. It is clear that instances of poor standards of basic care in hospitals cause a great deal of anxiety and distress to both patients and family members and real improvements need to be made in the basic standards of care provided to patients. If carers

relinquish responsibility as the primary carer in this environment, it is important that they can trust hospital staff to provide good care and to keep them informed about their relative's condition and prognosis.

7.4 Hospice

A number of participants in this study attended hospice day care, had a period of respite care, or a short stay in a hospice to assess their medication. For others, their relative received inpatient hospice care up until their death.

In contrast to the hospital model of care presented earlier, palliative care in a hospice (or a designated palliative care ward in a hospital) operates a different model of care. In this care setting, formal systems of care provide the main clinical care, and in keeping with the ethos of hospice care, also provide a supportive role in the patient and families' emotional and spiritual wellbeing.

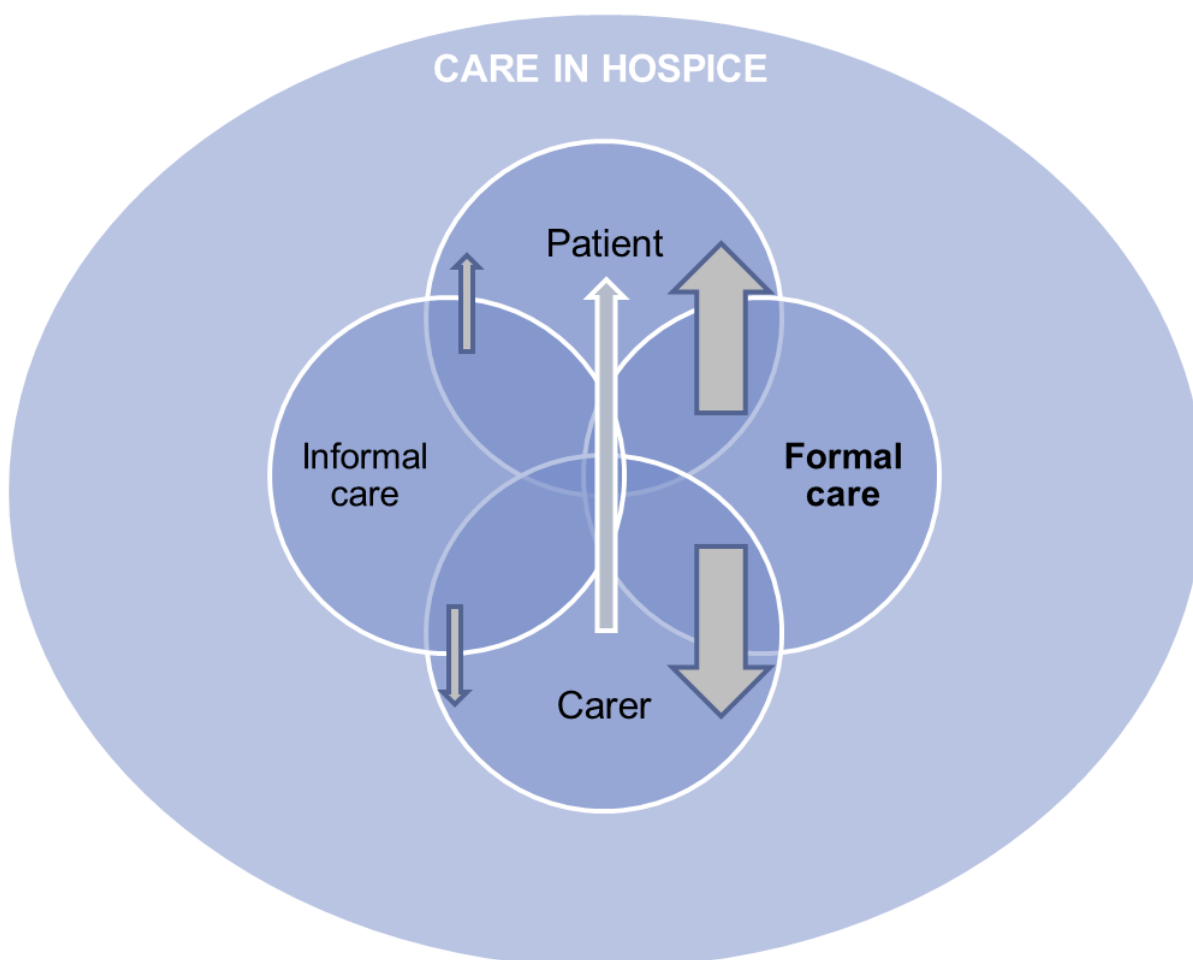


Figure 14: The interaction between formal and informal care in hospice

In many cases, family carers commented on their satisfaction with the quality of care in a hospice; carers often expressed feelings of trust in the hospice staff and felt that their family member was in 'safe hands'. Regardless of their relative's previous place of care, the majority of carers felt a sense of relief if a hospice became involved in care, as prior to this their journey had been filled with uncertainty, worry and heavy responsibility. This study suggests that uncertainty and worry is minimised in the hospice environment, as formal systems of care take on primary responsibility for both practical and clinical aspects of care. In the hospice care setting, other informal care this is received from family and close friends, but this is limited, and is mainly at an emotional or supportive level rather than practical level.

In some cases carers chose to continue to be involved in primary caregiving, such as helping with meals or personal care such as shaving. In hospices family carers take a secondary role in care provision, and if and when carers do chose to be involved with e.g. personal care and visiting they do so because they want to. This is an important finding and the impact of this difference to family carers should not be underestimated, as the following quote from Ann demonstrates:

"And then from that day, it seemed as if mum was treated totally different...they were absolutely brilliant with her; with us as well. And it was...it was priceless. And the help we were given, the advice...it's as if they put their arms around us and lifted us up." Ann

Ann helped care for her mother at home. Her quote describes the change in how she felt between the worry and responsibility of caring for her mother at home to her being taken into a hospice.

"The hospice provided us with a shoulder; [for] myself and my sister. I can't really comment for [step-father], but for myself and my sister, once she was in there, we were there twelve hours a day. We didn't really want to leave her, but we used to swap shifts and [step-father] used to take over...but we knew she was in safe hands. We knew she was at peace. But they were just- they were just fantastic." Ann

This quote further demonstrates the importance for carers of feeling that their relative is in 'safe hands' with the people they are handing over the responsibility of care to. The experiences shared by Ann in the hospice are in stark contrast to the experiences of other carers who described their presence being linked to a lack of trust in care provision in hospitals.

The findings presented in this thesis suggest that there is a very different culture and attitude between hospital and hospice models of care, as well as the approach of individual staff members. The narratives suggest that hospice nurses have a distinctly more personalised approach, which is very important to families and contributes to feelings of a 'good death' (Johnston & Smith 2006; Payne, Langley-Evans & Hillier 1996). There is a general ethos of caring and compassion in hospice settings, which was very reassuring to patients and families, which on the whole, was viewed by participants as lacking in hospital environments. In hospitals participants perceived the care and compassion of staff to be more variable and dependent on individual staff members rather than an ethos or culture of care and compassion.

Pauline's narrative provides a useful example of the difficult decisions family carers may have to make. Her experience highlights the differences between care practices in hospitals and hospice care and the impact this can have on patients and their families. Pauline's husband had small cell lung cancer and brain metastases and had several hospital admittances during his illness. He was cared for on a palliative care ward of a hospital at the end-of-life. Pauline's story has been rearranged in order to present it chronologically. She first discusses her experience of hospital care:

And erm depending on what staff were on – some staff were much better with him than others. Some staff felt very sorry for him and would really, really look after him and make sure he was fed and toileted carefully. The rest of the time I would come in and find him covered in food. He'd eaten his dinner, or attempted to eat his dinner, and I would go in each day with a clean set of pyjamas and underpants and take the (inaudible) home with me each day and I made sure I visited as much as I could – which was twice a day – I'd go twice a day and erm (daughter) would come in her lunch hour and help me you know get him out of bed and wash him and change him, shave him. Erm basically reassure him really – where he was and that he'd be home soon you know.

And they [hospital staff] said to me, "We simply don't have the staff to deal with your husband's condition." And I would say to them, "I understand that but that's not my fault and I don't know where else he can go." And they were saying, "Well there isn't anywhere else he can go." So, in the end, the last two times he went into hospital I was actually asked by the ward staff to

stay with him all day long – which I did do – and I left him at night when he went to sleep.

He was in the hospital for about a week and they said to me, again, “We don’t know how you’re coping with him – it’s taken us four to lift him to get him to the toilet and he doesn’t understand how to eat his food any more”. So I said – “No, you’re going to have to feed him, he can’t understand that you need to put a spoon up to your mouth”, you know. I said – “I’m feeding him at home, you know, doing everything for him”. So they said – “Right well you’re going to have to look for a hospice place for him – you won’t be able to take him home in the state that he’s in. Erm we would like to think that you could cope at home but this is not like an ordinary cancer patient and we don’t think you’re going to be able to manage at home”. And I was absolutely devastated, absolutely devastated to think that he couldn’t come home and die in his own home after all we’d been through.

But it was explained to me that I couldn’t have round the clock nursing care for him. I could have the district nurses popping in and the Macmillan nurses popping in. Erm I could even have a sort of team of carers that would come and help me lift him at night and everything. But my own mum has carers in and so I know the help is variable and I also know it can be often unreliable and people don’t turn up. So that was the choice that was given to me. And I had to basically make the choice, not on what I wanted but what I thought was best for (Husband). And a place in the palliative care ward wasn’t offered at that stage. I was told to go and look for a hospice.

Pauline’s husband was later offered a place on the palliative care ward of the same hospital. The hospice staff were flexible with visiting hours, which meant a great deal to Pauline.

Ward Sister: “You can stay with him and you can come and go as often as you want to or you can stay with him twenty-four hours”...and we had our own little room with a little bathroom. And the children left work; took time off work and we just stayed with him until he died.

(Upset) Sorry! That was (Husband)’s story really, you know. It was very, very sad; [a] terrible experience for us as a family. But that last week for

him was lovely; he got the best attention, he got one-to-one nursing; he got so much support as did our family– from the palliative care team. You know nothing was any trouble for them...They were looking after me and the kids as well as looking after him, you know. And then erm after he died they kept on ringing us for a long time [and] somebody came to his funeral – from the palliative care team which was lovely.

I think we just felt that a huge weight had been lifted off our shoulders when he went into palliative care; I could stop being a carer and I could become a wife for those last weeks. It wasn't that they stopped us caring for him, but they took all that responsibility away from me and I just felt as if a huge weight had been lifted. That was just absolutely wonderful.

... I could sit by him and I wasn't worried about making meals like I was at home and worrying about giving him his medication and worrying about getting him on the toilet in time. And I could just sit and talk to him. I just talked and talked and talked- talked about from when we met – we were going out from when we were eighteen...

In reading Pauline's account, the reader can feel the anxiety and worry through her use of language when describing her husband's pre-end of life care on a hospital ward. Pauline described her bridging and supportive role; visiting her husband as often as possible in order to ensure that he was being properly looked after, as she felt there was a lack of consistency in the standard of care. Conversely, when the place of care shifts to the palliative care ward of the hospital, the reader can again see how Pauline's language and tone changes to reflect her relief at the change in environment. In contrast to the pre-end of life ward care, Pauline suggests that her husband was being cared for appropriately and also notes that she was also looked after by the hospital staff. She felt anxious about her husband's place of care when the ward staff tell her that they can no longer care for her husband on the ward. She felt that the ward was not the right place for him to die, yet she was unable to gain assistance to help her provide an appropriate level of care at home. This complex scenario causes her a great deal of anxiety, as understandably, she is faced with a very important decision to make.

Interestingly, Pauline suggests that in the palliative care ward, her role identity shifts to return primarily to that of a 'wife' being with her husband at the end-of-life rather than a 'carer' who

must fight for adequate care, acts as the patient's advocate or provides bridging care in hospital. This suggests that Pauline was happy with the standard of care being provided and a level of trust is established with the staff. This is an important shift; one that brings into question the longer term impact of the experiences of inadequate or poor care in hospital for people with life limiting disease impacts on patients and their families.

In contrast to the power and status dynamics between informal and formal carers in the home and hospital environments, hospices appear to strike an appropriate balance; they work closely with the patient and the family and have a more personalised approach to care. It appears that hospices recognise that the important value of family carers, are attentive to their needs and involve them in the patient's care. Achieving this balance, hospices provide a special environment for families, as they take away the 'hard work of caring' (Crowther 2011) and allow people to be themselves, allow special or quality time for families to be together without all the extra worries that come with caring.

It is important to recognise however that the findings presented here are based on the experiences of the study participants. It is not the intention to suggest that hospice care is universally perfect or without fault. However, the positive experiences presented here do support those of other studies in this area (Addington-Hall & O'Callaghan 2009).

7.5 Nursing home

Similar issues about having confidence and trust in formal care arose in regards to nursing home care. Marie's mother suffered from a neuro-degenerative disease called Corticobasal Degeneration (CBD). Her mother also had lung cancer and respiratory disease. In the passage below she speaks about the importance of trusting the staff at the nursing home where her mother lived:

"I mean I think the most important thing was um.....knowing that you could trust where she was [pause] was looking after her when you weren't there. I think that was the most important-most important thing, so that you could relax when you were away, you know? That was by far the most important thing, you know; if I hadn't trusted the home I'd be moving in, you know, I'd have to move in there [residential home] or something. ..As I say, it's that she was getting cared for sort of all the time you know, that was the most important thing." Marie

There were too few cases of nursing home care to discuss in depth in this section, however, it is a significant finding that similar issues are arising across the illness trajectory, across

disease groups and across different places of care. The small number of nursing home cases is recognised as a limitation of this study and is an area that warrants further research.

7.6 Discussion of models and theory

The models of care depicted in this chapter make useful contributions to theory.

The models demonstrate that the roles of family caregivers change depending on place of care. The *meaning* attributed to their actions in their capacity as a family carer may vary depending on their level of trust in the capabilities of health and social care professionals to provide, what they perceive to be, an acceptable standard of care. This is particularly relevant in considering 'carers' willingness to care and ability to care' (Nolan 2001, p. 94); although care for the relative/patient is achieved, the meanings behind the roles that are adopted by family caregivers offer a further dimension to our understanding of carers as 'partners' in care.

The 'carers as experts model' takes the view that new carers will learn from health professionals, whilst experienced carers may have more appropriate and tailored knowledge of a person's needs than the professional. The findings presented here add a further dimension of understanding of the roles and tasks that caregivers adopt in different care settings.

This chapter has highlighted that complex role of family carers providing support for family members with life limiting illness throughout the illness trajectory. The chapter has examined interactions between formal and informal systems of care in supporting patients and their family carers. From diagnosis to end-of-life, this chapter has argued that the role of family caregivers develops throughout the illness trajectory and becomes increasingly complex and filled with responsibility.

In summary, family carers play a vital role in delivering practical day to day care and ensuring the emotional wellbeing of their loved one, enabling their family member to live at home for as long as possible. Family carers may receive some support from other family members, friends or from formal carers and community support teams. When these systems of care interact it is possible to deliver the best possible quality of life for the patient and indeed for the carer.

This chapter has examined the role of family carers throughout the illness trajectory and in different care settings. The following chapter will focus on aspects of uncertainty and the need for reassurance in taking on this responsibility. It will be argued that the uncertainty associated with being a family carer has a negative impact on both the carer and the cared

for person, whereas reassurance from clinicians can have a very positive impact for patients and their families.

Chapter 8

Findings II: Uncertainty and Reassurance

"They-they didn't do much more than what I was doing, but it was a relief to get them." Robert

8.1 Introduction

The previous chapter highlighted the roles of family carers and the interaction between formal and informal systems of care at home, in hospitals and in hospices. This chapter seeks to further this insight by exploring the important issue of uncertainty that was prevalent in the experiences of the family caregivers who took part in this study.

The chapter is presented in three main sections: the need for support; quality of care; and issues regarding employment and financial uncertainty. The final section in this chapter addresses uncertainty surrounding employment and financial aspects of caring for a person with a life-limiting illness. This issue emerged as an area of importance to participants, particularly in relation to the carers' ability to provide informal care and to pay for various aspects of care and support. Its justification for inclusion in this thesis is that financial and employment issues are important in the context of caring for a person with a life limiting illness. Excluding this section would neglect to provide the reader with a true context by which to understand the other issues relating to the interaction between formal and informal systems of care.

Feelings of uncertainty and subsequent anxiety associated with caring for a family member with a life limiting illness were key findings of this study. Mishel (1988 p225) defines uncertainty in illness as "the inability to determine the meaning of illness-related events". She goes on to say:

"It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately (Mishel, 1984)". (ibid)

Although useful, this definition theorises uncertainty from the point of view of the ill person. There is limited literature on uncertainty experienced by family carers. This chapter explores uncertainty and reassurance from the perspective of family carers.

Anxiety attributed to the unknown when caring for a person with a life limiting illness was a prevalent theme throughout the interviews, for all disease groups and at all stages of the illness trajectory. This finding is concurrent with Mishel's theory of uncertainty (1981, 1984, 1988), which asserts that uncertainty is experienced by patients throughout the illness trajectory. Mishel's theory initially focused on patients with deteriorating conditions (1988) but was later revisited to include uncertainty in long term and chronic illness (1990). The main principle underpinning the theory is that uncertainty occurs when an ill person is unable to assign meaning to an event (1988, 1990). However, Mishel (1990) notes that uncertainty is not an inherently negative state. For example, in some situations uncertainty may be linked to hope; in this case uncertainty is understood as an opportunity and is therefore positive (ibid). In other cases, uncertainty may be linked to danger and therefore a negative emotional state (ibid). Essentially, uncertainty is 'not considered to be a dreaded or a desired state until the implications of the uncertainty are determined' (Mishel 1990, p. 256). Furthermore, attaching meaning to an issue or event is an on-going process which may change over time. In this way, events which are initially perceived as negative, may over time, become to be perceived positively and vice versa (Mishel 1990, p. 258).

Mishel (1990) drew on chaos theory (Stengers & Prigogine 1984) in order to develop the theory of uncertainty in illness to include chronic illness. She considered cultural values around certainty and uncertainty in the western culture, noting the importance attributed to control and order. In contrast to these values chaos theory embraces 'disorder, instability, diversity, disequilibrium and restructuring as the healthy variability of a system' (Mishel & Clayton 2008, p. 58). Uncertainty in chronic illness may spiral out of control, affecting all other parts of a person's life and becoming a negatively disruptive event (Mishel 1990; Mishel & Clayton 2008, p. 58).

Both original and updated theories of uncertainty are useful to consider in this study, as some participants cared for people who were diagnosed with advanced or terminal illness (with a poor prognosis or life expectancy after diagnosis), whereas others cared for people who 'lived with' their condition over many years and therefore may be described as a chronic illness (such as some cases of MND³⁷ and COPD³⁸). Carers were not explicitly asked about

³⁷ Motor Neuron Disease, a neurological disease

their views on uncertainty, but often spoke about it at length. This chapter highlights areas of prevalent uncertainty for family carers and their relatives.

This chapter focuses on the important relationship between uncertainty and reassurance for family carers. For the purposes of illustrating this argument it may be useful to consider uncertainty and reassurance as weights on a set of scales (figure 15). Although some form of uncertainty for people with life-limiting illnesses and their families is likely to be unavoidable, the findings of this study suggest that the degree of uncertainty and the consequent impact of this on patients and carers may be counterbalanced by adequate support through reassurance gained from proactive care and support of formal systems of care.



Figure 15: Balancing uncertainty and reassurance

8.2 The need for support

There is a large body of literature addressing the needs of carers and patients, particularly at the end of life (Bee, Barnes & Luker 2009; Funk et al. 2010; Grande et al. 2009; Hudson & Payne 2011; Stajduhar et al. 2010). The literature review chapter identified a lack of existing research that retrospectively examines the whole of the illness trajectory. Furthermore, the literature in this area is beginning to shift from the identification of carers' needs to focus on the effectiveness of interventions (Candy 2012; Candy et al. 2011; Grande et al. 2009; McMillan 2005).

McMillan (2005) discusses educational and supportive interventions for family carers at the end of life. The aim of McMillan's research was to assess which interventions were most

³⁸ Chronic Obstructive Pulmonary Disease, a respiratory disease

effective for different groups of family carers. The inclusion and exclusion criteria are unclear; however, there is a focus on carers of people with cancer and Alzheimer's disease. The review evaluates descriptive and intervention based research, given at the end of life, which intended to reduce measurable outcomes such as depression and quality of life for family carers, post bereavement. Similarly, a systematic review by Candy et al. (2011) assessed the effectiveness of randomised controlled trials (RCTs) based interventions, aimed at improving the psychological and physical health of family carers at end of life. RCTs are often regarded as the 'gold standard' in determining the effectiveness of an intervention (see for example Bowling 2009; Bryman 2008; Kumar 2005). Although both of these reviews have identified the importance of supporting family carers, both evaluate research that primarily concentrates on carers of people with cancer at the end of life. Interventions aimed at people with other life limiting illnesses, as well as at other stages of the illness trajectory, are neglected. Furthermore, a focus on measurable outcomes of interventions at the end of life neglects to consider the importance of the experiences of carers and patients, the quality of interactions with health professionals and any educational and supportive components that were experienced prior to the end of life stage.

To treat family carers' experience of end of life as separate to their caring experience as a whole is somewhat problematic. I would like to suggest that carers' experiences throughout the illness trajectory impact on their experience at the end of life and therefore 'end of life' cannot be viewed in isolation to the experiences that precede it. Although this suggestion is based on descriptive data rather than data that can be evidenced through clinical trials, the findings of this PhD study indicate that the overall quality of support, interactions and communication between families, patients and formal systems of care need to be improved, at all stages of the illness trajectory. I would therefore argue that the current focus on developing and evaluating supportive interventions only addresses part of the problem; the research presented here suggests that improved support and communication from healthcare professionals and improved triadic care would greatly improve the experience of carers and patients by addressing their needs throughout the illness trajectory. Furthermore, a return to improving care at a basic or 'grass roots' level, rather than additional interventions leads us to consider, in the first instance, the similarities and differences in support needs of carers and patients with different illnesses. The problem with this proposal is the possible difficulties associated with measuring such outcomes to provide evidence for this theory.

8.3 Care and support may improve at the end of life (compared to pre-end of life care)

The findings from this study indicate that support for family carers throughout the illness trajectory, as well as at the end of life is varied. For some, support at home vastly improves when a health professional is able to label a person as being at the 'end of life', resulting in patients and their families receiving improved access to care and support at this time. However, findings were inconsistent, as the quality of end of life care (as perceived by carers) varied greatly across the sample. It is difficult to determine whether research evidence supports this finding, as the large majority of studies focus specifically on end of life care, with little or no comparison to care experiences or satisfaction with care prior to this.

Interestingly, the findings suggest that pre-end of life care³⁹ may hold the most uncertainty for carers of people with life limiting illness. The following exemplars help to illustrate this.

Ann, for example, supported her step-father to care for her mother, who had a neurological condition (PSP). After experiencing what she perceived to be poor care in the pre-end of life phase, Ann asserted that they received more formal support at the end of life. Her mother was cared for at their local hospice at the end of life:

"The help and the caring, that's all I can really keep referring back to, came at the end, when it mattered." Ann

Ann's comment 'when it mattered' is particularly interesting, as this could be understood as when it mattered most for her mother; that her mother received good care and a peaceful death, rather than earlier in the illness trajectory when she was thinking about the difficulties they experienced caring for her at home.

Barry similarly noted increased care and support from formal systems of care towards the end of his mother's life. His mother had ovarian cancer and later died at home. When asked if the amount of care and or support he and his mother received increased towards the end of her life, Barry replied;

"Towards the end, yes. There was two [district nurses/ formal carers] of a morning, two in the afternoon and in the evening...But they did- more people came." Barry

Barry went on to describe how the frequency of supportive visits from district nurses, Macmillan nurses and the GP noticeably increased in the last few weeks of his mother's life.

³⁹ Defined in introduction.

However, research evidence suggests end of life care does not improve for all patient groups. Whitehead et al. (2012), for example, found that support from formal systems of care was inadequate for patients with MND⁴⁰ and their family carers throughout the illness trajectory and specifically at the end of life. Some carers reported inadequate support from health and social care services, limited GP involvement and a lack of continuity of care (Whitehead et al. 2012, p. 372). Their findings suggested that additional nursing support at the end of life would have been particularly beneficial to family carers (ibid). Similarly, evidence from this PhD study strongly suggests that more practical support, particularly around the presence of nurses at end of life would be reassuring for carers, in terms of emotional support, helping with practical and medical aspects of care and, most importantly, reassurance.

It is important to acknowledge that there have been significant developments in research in end of life care over recent years. For example, recent research has focused on identifying the needs of carers and patients at the end of life (see for example Bee, Barnes & Luker 2009; Buscemi, Font & Viladricht ; Ewing et al. 2012; Ewing & Grande 2012; McIlfatrick 2007), as well as increasing amounts of research that designs and tests interventions to improve care for this specific population (Candy 2012; Candy et al. 2011; McMillan 2005). Such research is set against the backdrop of policy documents and government backing to improve care in this area in recent years (Cross-Government Publication 2010; Department of Health 2008b; NHS 2011, 2013b).

Although the picture that has emerged from the findings is somewhat unclear, it raises a number of important questions for consideration: does more attention need to be paid to pre-end of life care for people with life limiting illnesses? And can the lessons learnt from research in end of life care be applied earlier in the illness trajectory for people with life limiting illnesses and their family carers? This is an interesting and unexpected finding of this study, however it is difficult to objectively assess carers' needs and whether these needs were met at different points in the illness trajectory from the retrospective narrative interviews undertaken in this study. Other research designs may be more appropriate to address these specific questions (e.g. a retrospective study using a questionnaire with both open and closed questions, a focused qualitative interview, or a longitudinal study including a focused retrospective interview). A further analysis of similarities and differences between patient groups (disease, age and gender for example) would also be very useful in helping to understand the current picture of care and support across the illness trajectory. I would suggest that this is an important area of focus for future research on this topic.

⁴⁰ Motor Neuron Disease

8.4 Access to care and support

This section highlights the uncertainty experienced by carers as they attempting to access help and support through the health and social care system. The findings suggest that appropriate and timely care and support often failed to be proactively provided to carers and patients at the time when they needed it. Furthermore, carers often described having to 'fight' to secure the support that they needed. Some carers were successful in gaining the support they required, however, others found that the support they needed came too late. This lack of proactive care and support was a source of great uncertainty to family caregivers.

8.4.1 The carers' 'fight' to access timely care and support

Many carers in the study described how, in many respects, they became an advocate for their relative. The advocate role included what many carers described as 'fighting' for care and support. This was reflected in language that may be associated with conflict, such as 'fight', 'battle' and 'struggle'. Language such as this was present across the sample. Many carers felt that support was often difficult to access; red tape, paper work, being passed from person to person, and a lack of information all hindered carers' ability to access timely support. This was a source of great frustration for both patients and carers. Many carers described how their 'fight' for care or access to services was eventually successful and resulted in acquiring the help they needed. However, the course of the 'battle' was both frustrating and exhausting for carers, who described the difficulties of having to 'fight' for the support they needed in addition to caring for their relative.

Pat cared for her husband at home. Her husband had cancer (brain tumour). She described how she 'fought' to secure the funding required to maintain support to help care for her husband at home.

"I think that I'm quite a strong person and if I hadn't have been then it may well have been taken away. You know, not everybody can fight their corner, can they? And if they can't, then they would have probably lost out on it".

Pat

In this quote Pat described herself as being a 'strong person', which she attributed to helping her to secure this support. It is interesting that she recognises this and worries about people who may not have the 'strength' to do this.

In a further example, Jean cared for her mother who had Chronic Obstructive Pulmonary Disease (COPD). She described her experience of trying to access support at home to care for her mum, as she worked full time.

“We had a long hard fight just to try and get help and support [tearful]. The communication was just....I felt some days like I was going to put my head through that window ‘cause no-one was listening....and I tried to do it all away from her not seeing.” Jean

Both cases highlight the stress and anxiety associated with accessing and securing help and support from the health and social care system. This finding was common for carers across the sample demographics. This is interesting, as it indicates that carers needs are not being assessed or met in a timely fashion. Tools such as the Carer Needs Assessment Tool (CSNAT) (Ewing & Grande 2012) may be useful in identifying a carer’s needs, however, the findings of this study indicate that securing adequate funding and providing timely support to meet these needs may present further challenges.

Not only did carers describe their ‘fight’ for care and support, but in many cases carers described that where additional care and support was offered, it often materialised too late and in some cases was considered inadequate. The delay in accessing support significantly impacted on the quality of life of carers in terms of stress, anxiety and frustration, but also on the quality of life of the person being cared for. Janet’s father was initially reluctant to accept additional help and support from formal agencies, despite his daughter expressing that she was struggling to cope as his sole carer (whilst also looking after her own family). Janet described her relief when her father finally agreed to accept additional support, however the following extract reveals that there was a significant delay (a number of weeks) in receiving the necessary form(s) to begin the process.

“He agreed in those last weeks for me to contact the Social Services, which I did do erm, because that hadn’t been offered to me [additional support at home]...eventually at the end he, he said to me that he would agree to meet someone from Social Services, erm and the day of his funeral the application form came through. So it was all just too late really.”

Janet

This extract provides an example of the many cases in the study where carers expressed difficulty in accessing support from formal systems of care when needed. Whilst it is important to recognise that care and support take time to put into place, these findings highlight the need for a service which can react quickly to the needs of service users. It is evident that many carers in this study found the length of time it took to put care and support

into place was unacceptable and that this significantly impacted on the quality of life of both carers and patients.

As highlighted in the previous chapter, the provision of night care was also a particular problem for carers and their relatives. In the following extract, Jean reflects on her experience of caring for her mother at home. The problem of accessing night support was a source of particular stress for her:

“But it [caring for mother] was long and hard.

[pause]

They promised me night carers [pause] they sent them to me on night she died. Phoned- got a phone call “Oh we’ve got you night carers tonight so you can have a good nights’ sleep”. “Don’t bother; she’s dead”.

[pause]

Everything was all a bit too late.

[pause]

Whereas that should have been up and running from the day I brought her- she was home for two and a half weeks from [hospital] before she died. [pause] That should have been in place. I shouldn’t have to have been running around like a headless chicken.” Jean

Jean’s story offers the reader an insight into the sadness and frustration she felt regarding access to night care. By pausing as she recollects events and by emphasising particular words, Jean highlights the strength of her feelings. My interpretation of Jean’s experience is that she resented that she and her mother did not get the care she believed they were entitled to, at the time they were most in need; that they were let down by the health and social care system. She is resentful about this because this added to her stress at what was already a very difficult time. Should the services have been in place this may have alleviated some of her stress and anxiety and allowed her to spend quality time with her mother at the end of her life. Unfortunately, Jean describes that she was ‘running around like a headless chicken’ at this time. Jean’s experience provides an example where end of life care failed to meet the needs of both patient and carer.

Similarly, many families without a specialist nurse did not know where to turn for the support they needed and often turned to social services or the district nurses. This often resulted in a

significant delay in accessing the services they needed at the time they were needed. The key issue here is that many carers were unclear about what care and support may be available to them, as well as how to access it. This issue has been identified in regard to providing practical care at home when caring for someone with cancer (Luker et al. In press). As well as providing up to date information on practical and physical aspects of care, this booklet based intervention signposts users to the appropriate health and social care professional or appropriate organisation that can assist them with their need. In contrast, those participants who had access to a specialist nurse (such as a Macmillan nurse, respiratory nurse, or neurological nurse) appeared to have a more direct route to the support they needed. In such cases, the specialist nurse began the appropriate proceedings, resulting in a minimal delay between the request and service provision. In most cases, this resulted in a more positive outcome for patients and families, as they received the support they needed in a timely fashion.

As a person's illness progresses, their needs may change rapidly, particularly towards the end of life. This highlights the need for caregivers to be clear about who to contact in a particular situation and for the appropriate agency to react quickly to meet the needs of carers and patients. Furthermore, at a time of NHS budget cuts and efficiency savings this also leads us to question the financial impact of this practice on NHS resources. Time spent on administration that cannot be seen through, medication and other items that were no longer required or were unused have to be disposed of. The impact of help coming too late has a significant impact on all parties and is imperative that this issue be addressed. This issue fails to be fully addressed in The Carers Strategy (2010), in terms of financial aspects or the impact on patients and their families. However, it is important to recognise that in the time since this research was conducted, the government has begun to roll out direct payments or 'personal budgets' which will enable patients and their families to purchase the help and support that they deem appropriate for their circumstances.

The findings presented here highlight the importance of carers and patients being made aware of what help and support may be available to them and who to contact should they decide to access it. It also promotes the case for regular caregiver needs assessments to be undertaken throughout the illness trajectory, rather than as a one off, as well as the importance of timely reactions requests for support.

8.4.2 'Ring us if you need us': the problem of reactive care and support

As noted earlier, carers' needs are well documented in the literature (see chapter two). However, *how* these needs should be delivered is less well documented. The findings from this study suggest there is an urgent need for *proactive* rather *reactive* support from formal

systems of care. 'Reactive' refers to 'acting in response to a situation rather than creating or controlling it' (Oxford Dictionaries 2012), whereas 'proactive' refers to 'creating or controlling a situation rather than just responding to it after it has happened' (Oxford Dictionaries 2012). This distinction holds important consequences when considering health and social care provision in the UK. The need for proactive support was a key finding of this study and is directly related to the research question of how formal and informal systems of care work together to meet the needs of carers and patients. The prevalence and importance of this issue was evident throughout the illness trajectory and encompassed both practical and emotional aspects of care and support. This finding was not associated with any particular demographic factor and was prevalent across all disease groups, indicating that this issue is likely to be generalizable to a wider population of family carers.

A proactive approach to support is also necessary at the end of life, particularly in the home setting. The following quote is from Carol who cared for her son at home; he had inoperable stomach cancer. Carol emphasised the need for proactive support at the end of life:

"P [Some] months after his death I had a meeting with the GP and pointed out many factors, and one was there was no telephone call from the Wednesday 'til the following Monday, when he died, to ask how he was or ask how we were coping. There was no visit to the house off [from] a Doctor from that Wednesday, no Macmillan to visit, no night sitters available. I didn't know about terminal restlessness; what, what was that? We were just told "he's got terminal restlessness"⁴¹, I didn't know what that was...Someone to reassure us we were given everything possible medication wise to make him comfortable. And pathways, what help should we have been given? They were the questions I asked the GP months after his death

I And what their response?

P She would take them [comments] back, but "they don't phone". [Pause] But, for thirty pence you would be worth a phone call to ask how you are coping".

Carol

⁴¹ 'Terminal restlessness' may occur in the last days or hours of a person's life. During this time a person may become restless and agitated and they may experience muscle contractions. They may also call out and seem confused or distressed. This can be distressing for families (Cancer Research UK 2013a)

The fraught nature of this quote gives the reader an insight into the various aspects of uncertainty Carol felt regarding end of life care for her son, as well as the distress she felt and continued to feel about the circumstances. The quote highlights the need for reassurance from medical professionals around death and dying, including information about what is likely to happen as a person approaches death and the need for support or reassurance from formal systems of care. The need for proactive support, such as a phone call or visit is central in supporting carers' needs when caring for a relative as they approach death.

The need for proactive support is central in addressing the research question, as the findings of this study suggest that many family carers require proactive support from formal systems of care, at home, in order to care for family members with life limiting illness at the end of life.

Carol's assertion that *"for thirty pence you would be worth a phone call to ask how you are coping"* is interesting as it provides an insight into the meaning Carol attributed to this. Putting a nominal monetary value on an action implies that a small action could have an enormous impact on her experience. Furthermore, it perhaps suggests she felt devalued by the health and social care system that they could not spare the time or money to check on her at what she considered to be an important time.

Carol also suggests that the current system of reactive care may be more acceptable if there was an established relationship with health professionals:

"When you do ring you mightn't get one of the team, whereas if one of the team would have rang and said 'how is he this afternoon or how are you or do you need any [help]...', cos it might not've always have been one of the team, it could have been one from somewhere else and 'oh we'll pass the message on'. You don't want that." Carol

This quote highlights the importance of carers being able to speak with someone known to them. This issue is closely linked with issues around continuity of care, which are discussed section 8.5.

In a further example, Graeme cared for his wife who suffered from Motor Neuron Disease (MND). When his wife was diagnosed with MND, their doctor signposted them to a UK based charity that support people with MND and their families. Following this advice, Graeme contacted the charity, hoping that they would offer him some support and advice about caring for his wife. Speaking about his initial contact with the charity he explained:

"She was a lovely person. She told us what kind of help the [charity] give ya. But after that, I didn't feel that the care was there, because they weren't in regular touch with ya. You'd get a call maybe once every three, four, maybe five months even. It was as if you didn't exist, and all of a sudden, out of the blue you'd get a phone call."

Speaking about the support the charity offers Graeme said:

"Even though they'd say 'we're here for you', you don't know what to ask for...and that is the hard part...They help you out with any needs that you need, er special chairs, er special items that can help feed ya, they will fund it [pause] er, but I just didn't feel as though they were there for you, if you know what I mean?"

This quote suggests that whilst proactive telephone support may be a valuable support to family carers, that this contact needs to be fairly frequent and consistent, in order to build a supportive relationship. Referring back to the earlier discussion of continuity of care in proactive support, telephone support may be more useful if for example, there was a case worker assigned to clients, enabling a supportive relationship to be built over time.

A pilot study conducted by Walsh and Schmidt (2003) indicated that carers caring for their relative at home benefited from telephone support from hospice nurses. However, this was a small pilot study consisting of 14 carers and, due to attrition, only 5 carers completed the follow up. Findings from the data collected for this study strongly supports the notion of proactive telephone support from health professionals at the end of life. There is limited research literature regarding proactive telephone support for caregivers people with a life limiting illness. Literature in this area is focuses on tele-health, supportive phone calls from experienced carers to new carers (Stewart et al. 2006) and out of hours telephone support lines. It is perhaps important to note that, in the main, such studies found that carers reported high levels of satisfaction with these services. It is possible therefore that telephone calls from community nurse teams (or appropriate charities) may have a similarly positive impact on family carers. Proactive support may also be provided through peer support, such as through 'buddy' schemes, for example, as there is some evidence to suggest that peer support has a positive impact (Hoey et al. 2008; Macvean, White & Sanson-Fisher 2008). However, peer support was not directly referenced by any participants in this study.

Ann's story provides a further example of the problem of reactive care and support. A registered neurological charity provided invaluable support for Ann and her family. Ann took

the lead in contacting the charity as her step-father (her mother's main carer) did not have a computer, and was reluctant to contact the nurses himself.

"[My step-father] wasn't for ringing up. He was too busy and he was tired and he was having to look after mum. And he was her next of kin. But he had no intention of going on a website. He hasn't got a computer to look at this. There was no leaflet, there was nothing [from the hospital]. Nothing. But only because I would you know, ring [specialist nurse at charity] up; that's where the information came from, to help us. I feel they - the way they make you feel that [speaks slowly to emphasise] you're-not-on-your-own, and you're not-they just sort of [pause] helped us, in a spiritual way as well I think, to lift the burden a little tiny bit". Ann

This exemplar demonstrates the positive difference that other informal support such as charities can make to the lives of carers and patients. The quote also highlights some of the difficulties around telephone contact as a method of support; the fact that it is up to the carer to make the phone call is a barrier in itself. In this example, the family would not have had the information or support they needed if Ann had not made initial and on-going contact with the organisation.

Further complexities of asking carers to 'ring us if you need us' emerged from the data. As with many carers in this study, Linda felt confused about *who* to contact, should she need help:

"I think again an explanation of exactly what's on hand and what you can ask for erm, a detailed explanation of what's available and who provides it, because erm the Macmillan nurses said "Well if you need some help you've only got to ask", you know, well who do you ask [pause] in that circle? Is it the Macmillan palliative care nurse? Is it the district nurse? Is it your GP? Nothing is made clear. Linda

Graeme also experienced difficulties in knowing who to contact for support. The resulting lack of support and feeling of being turned away led to Graeme having thoughts about ending his own life. It is useful to provide extended quotes here to facilitate a more detailed insight into his experience:

"I went through a stage of...er, I was looking at- I was looking at- I was going to hang myself, through the pressure of what I was under. Er, cos everyone who I turned to- who we were turning to...[I] felt as though you

had to beg them and say like 'help me, help me' and you never got any of this help. People just seemed to turn away".

"There's nobody to say 'right'- they are sort of, they say 'I'm so and so, I'm here if you need me', but you don't know what they're there for, that's the hard part. And then as you're going along the road you find out that that is what these people are there for, but you don't know for definite. It's hard to- it's hard to understand that part; exactly what they can do."

"Eventually you seem to get put in touch with the right people, eventually, but it's hard work; you just don't know where to turn... It's like a big jigsaw puzzle. It's you know, they've thrown pieces on the table 'right, you sort it out'".

Although an anomaly in the severity of the impact that unmet need for support had on Graeme, the fragmentation of services and not knowing who to contact echoes the experiences of many other carers in this study. Such severe consequences highlight the importance of improving support at the grass roots level of care and support, in this case, providing clear guidelines about who to contact for different aspects of care and support.

Whilst poor communication regarding who to contact was a barrier for some carers, Linda offered a further perspective on barriers to accessing support. Linda cared for her husband, who had cancer, at home. She explained:

"Some people are frightened of asking um, because as a carer you don't want to seem asking for help. I think carers can perceive asking for help as a weakness". Linda

This highlights a further barrier to carers contacting supportive services and provides further evidence for the need for proactive care and support.

Whilst a number of other carers commented that they refrained from ringing a district nurse or Macmillan nurse, as they were aware of their heavy workload and would feel guilty to add to this. Asked if there would have been anything that would have helped with caring for her husband at home, Pauline commented:

"If there could have been more access to a Macmillan nurse, more visits from her – definitely. She was lovely, you felt to guilty ringing her and

asking her because she looked so worn out when she came, you know. She just had that many patients to see". Pauline

Graeme also shared this view. He commented:

"I feel that it would help if they phoned you on a regular basis. That type of thing. Cos you tended not to phone them, because you felt as if you was being a pain." Graeme

Paul's wife was also hesitant to contact the Macmillan nurse team. His wife had ovarian cancer and they were in regular contact with their local hospice. His wife also attended day care once a week at the hospice. In the following extract Paul describes the positive consequences of he and his wife contacting the Macmillan nurses:

"They sought of emphasised "if there's any problems at all, just give us a ring" and there was times when I was concerned, you know, over [wife] and she'd say "oh I don't want to bother them, and I went, eh look love they'd said to give us a ring", so I'd give them a ring and they'd say, "oh yeah, no problem at all er, this is what normally happens when you feel like this, but if it does get any worse..." And even before we had the chemo they were on the phone all the time, you know, and if, if we needed them and they'd ring up and say "how's things?" Paul

This extract provides further evidence of the positive impact of telephone support, as well as emphasising the reluctance that many carers and patients feel about initiating contact with appropriate services.

Although the findings presented here suggest that supportive telephone calls may have a positive impact on carers, Hudson, Aranda and Kristjanson (2004) suggest that carers are more likely to disclose issues during face-to-face interactions than over the telephone. Future service development may wish to take this into consideration.

A further finding is that only a small minority of carers in this study mentioned any form of care and support that they accessed through charitable organisations. Of those who did contact such organisations, it was usually on the recommendation of a health professional or another carer. Organisations such as Macmillan, Marie Curie, The British Red Cross, Cruse bereavement care, Carers UK and the NHS all have websites aimed specifically at supporting family carers and have freephone advice lines. Although this question was not directly posed in the interviews with carers, the lack of carers who spoke about accessing support through such organisations is notable. This indicates that there may be further

barriers to carers contacting supportive organisations. It may be useful to promote such organisations to carers, in order to raise awareness of other forms of help and support that are available. Luker et al. (In press) suggest that carers found it very useful to have a list of contact details for appropriate organisations, such as those listed above, in a booklet format.

This section has demonstrated some of the complexities around supporting family carers. In terms of interventions, findings from this study suggest that proactive telephone support from health professionals may have a positive impact for family carers. However, it could be argued that making clear who to contact should carers need help, as well as ensuring that health professionals have the capacity to deal with additional support should be standard practice in the health care system.

Evidence from this study suggests that proactive support, whether in person or by telephone may be an effective way of supporting people caring for a relative with a life limiting illness. Evidence from systematic reviews on the acceptability of tele-health also indicate the positive impact of telephone (and other) support in a palliative care population (Kidd et al. 2010). The findings from this study strongly suggest that there are a number of barriers to carers initiating contact with the appropriate organisation. A recommendation of this study is therefore for appropriate teams and organisations to proactively contact family carers, where possible. However, it is recognised that this puts the responsibility back on to the health and social care system and charitable organisations to manage case loads and deal with any issues that may arise from such additional contact. It is questionable whether NHS led initiatives or charitable associations have the capacity to provide this level of support, despite it being so clearly needed, particularly at a time of economic austerity. The issue of how health professionals would integrate this into their everyday role is also likely to be problematic (Morrison & Mair 2011).

8.4.3 Access to information, care and support: a case of luck and chance?

Access to care and support emerged as being inconsistent; many carers described the role that chance played in accessing some aspects of care and support. In particular, people with cancer were often supported by Macmillan nurses and experienced more consistent or streamlined access to care and support through their Macmillan contact. For others, particularly those with non-cancer illnesses, additional informal and formal support was fragmented and inconsistent.

In the following excerpt Graeme reflects on the many difficulties he experienced trying to access the care and support that he felt he needed:

"I think sometimes you're lucky if certain people get involved. And, as I say, it's through error you find these people." Graeme

This powerful comment is representative of the experiences of many carers who participated in this study; it reflects the inconsistencies that exist within the model of triadic care, which negatively impact on carers and patients. Clearly, a more transparent and integrated system of communication is needed between systems of formal and formal care in order to improve the quality of life of both patients and carers.

A number of carers of people with neurological and respiratory disease explained that they were put in contact with specialist nurses by hearing about the service they provide by others. Elaine, for example, became friendly with a lady whom she had met through a local neurological support group. Elaine had been caring for her husband at home for a number of years, but his progressive condition had begun to take its toll on her.

"[a friend] said to me one day when she'd been to see [my husband] and been talking to me and was very helpful, she said "I'd like to refer you to er the community neurological team nurse", she said "she was so good with [name of friend's husband]. Do you mind if I ring them up and tell them about [your husband]" so er, I said "No, I would be only too happy to get some help". So er, so she did. And this nurse came round the next day".

Elaine

The data suggests that there is a gap in service provision for people with progressive life limiting illnesses such as MND, MS and PSP. The often slow progression of such illnesses means that carers and patients are often able to adapt to small changes over time. This however, may result in them not coming into contact with a health professional for some time. Furthermore, such conditions are often difficult to diagnose and are diagnosed only when the disease is fairly advanced. Such reasons may be contributing factors as to why this group of patients and their families are not being pointed to support groups and charities by health professionals.

Access to specialist nurses and other informal support was slightly better for people with respiratory disease and their carers. A number of participants described how they were supported by a respiratory nurse, and described the positive impact of this. Continuity of care was again important here, as a local respiratory nurse was often able to build a supportive professional relationship with patients and their family carers.

A further example of good practice in respiratory care was demonstrated by a local primary care initiative (Acute Chest Triage Rapid Intervention Guided by Home Care or Telecare-ACTRIGHT) which supports people with COPD in their homes following a discharge from hospital (Callaghan 1999). Patients receive regular home visits and/or telephone calls from a member of the team and are given appropriate contact details, should they need to contact a member of the team themselves (ibid). These patients are also supported by community nursing teams during evenings and out of hours (ibid). Patients reported that their satisfaction with this service (Callaghan 1999; Davies et al. 2000).

Ann's experience provides a useful example of the positive impact that support from charities can have on patients and their family caregivers. Ann's step father attended the appointment where her mother was diagnosed with PSP. Her step-father was given little information about the condition by the doctor, but was given a website address to look up himself. This was problematic as Ann's step-father was elderly and was not computer literate, however, Ann was able to look up the website and found the support they offered to be invaluable. She explained:

"They [charity] were really, really helpful...We were given help and advice and guidance really... And I used to ring, and the lady used to ring me back. If she [specialist nurse] was out with a patient, or whatever, she would always, always ring me back. And that's where we got our information from. She talked to us about the symptoms and what would be the next stage and what to expect".

Ann went on to say:

"I think it [information about the condition] should have come from the hospital really, considering it's such a rare disease. I don't think you should be left with the website written down on a piece of paper and told to go away and look at that. [pause] Totally unacceptable. But once I did get in touch with them [charity], they were fantastic. Nothing was too much trouble for them".

This example highlights the role of chance in accessing such services; had Ann not obtained this information on her step-father's behalf they may not have accessed the support they required. The extract demonstrates Ann's awareness of this and considered this to be unacceptable.

In a further example, Pauline highlights the role of luck in chance in regards to poor communication. In the following excerpt she explains that she was left confused about the meaning of 'palliative care', but that her daughter, who worked as an occupational therapist, was able to explain this to her.

"At the beginning when we were told that he was going to have palliative treatment I didn't have a clue – nobody explained. But luckily my daughter is an OT [occupational therapist] so she knew and she was able to explain to me when I got home what 'palliative' meant. I didn't even – the term wasn't even familiar". Pauline

This section has highlighted the inconsistencies that some carers experienced within health and social care at the time this research was undertaken. In a number of cases, participants felt that they accessed the services they did by chance rather than through structured means. In contrast, the findings suggest that many carers who were in contact with a specialist nurse (such as a Macmillan or respiratory nurses for example), experienced more streamlined care. Furthermore, the impact of accessing supportive services often had a very positive impact on the quality of life of carers and patients, which further emphasises the importance of the need for consistent and structured mechanisms of providing people with appropriate information and supportive services. This is relevant to the research question because it demonstrates the importance of carers and patients receiving co-ordinated and streamlined care and support throughout the illness trajectory. The findings suggest there is an inconsistent picture. The data suggests that such inconsistencies and inequalities in access to care and support have a significant impact on the lives of people with life-limiting illnesses and their family carers.

8.5 Continuity of care

Continuity of care emerged as an important issue, which was closely linked to feelings of uncertainty for family carers. Carers' uncertainty regarding continuity of care was particularly prevalent in the home environment, where building relationships with paid carers and/or district nurses held particular importance for both patients and carers. Carers also spoke about this issue in regards to care on hospital wards. Carers reported that their relatives emphasised the importance of 'getting to know' and 'feeling comfortable' with those caring for their relative and building trust. Many participants emphasised the importance of feeling that their relative was in 'safe hands' with a person who is familiar with the patient, and was somebody that both the carer and patient had come to know and trust over time. This issue was prevalent across all disease groups in the study.

8.5.1 Home

Issues regarding continuity of care were particularly prevalent in the home environment. Rosemary spoke about her relationship with a community matron and the positive affect it had on her husband's care and her own state of mind. This is important as it demonstrates how systems of formal and informal care can successfully work together to meet the needs of the patient. Rosemary spoke about the practical difficulties associated with getting her husband, who had a complex diagnosis (Non- Hodgkin's lymphoma, a respiratory condition and had had a stroke) to visit the GP when they needed advice about his health. Speaking about the matron assigned to her husband's care, Rosemary explained:

"[contacting the matron] was a lot less hassle [than visiting the GP], less pressure and everything because we knew she was only at the end of the phone and if there was any queries I just had to pick the phone up and she was, she'd say "What's up?"...it was just a fantastic service that we had there. I don't know how people would manage getting through that stage without the support that the matrons give you."

Rosemary further commented:

"I just informed her, you know, I kept her up to date with erm with what was goin on day to day"

This excerpt provides a useful example of the positive impact that triadic care can have when a relationship is built between carers and health professionals over time. This finding is in contrast to carers who did not have a strong relationship with a professional involved in their relative's care, who would not call regarding non-emergency matters.

The following excerpt from Jane provides a useful summary of the main issues regarding continuity of care with formal carers who were arranged through social services:

"Some of them [formal carers] were excellent...some of them were a bit rubbishy. But you didn't really know what time they were going to come; they were unreliable about what time they arrived... They weren't reliable about who you were going to get. Mum would have liked to know who was coming; which carer she was having which day. And she couldn't know that; that was hard for her. She was trying desperately to get some structure back into her life; some order and some routine and something that she could get her head into, but she couldn't get it." Jane

Jane's mother suffered from a respiratory condition (lung fibrosis) and became increasingly confused as her illness progressed. Jane explained that the formal carers who visited their home were nearly always different. She also commented that carers were often unreliable about what time they would arrive, although my understanding is that there may be a morning or afternoon visit, for example, and that carers were not in a position to specify an exact time. Nevertheless, the impact of this experientially is that this is a further source of uncertainty for carers and patients. Jane's experience is representative of many of the carers who took part in this study; such uncertainty and unpredictability represent a significant source of stress for both carers and their relatives.

In a further example, Pat describes the disruption and distress caused by a change in care provision that was made without her knowledge. This change was particularly disruptive as her husband's brain tumour had led to him being confused.

"Now, my husband had got into a routine, and he preferred- because he'd got used to this one woman, who'd been with him for six months- I was appalled that they didn't have the decency to speak to me about it... I didn't want her [new carer] there; I just wanted status quo, you know, didn't want a change. And they [care agency] didn't seem to understand that at all." Pat

Pat's quote is important as it highlights the need for systems of formal and informal care to work together and be aware of one another's needs. Pat strongly felt that she should have been consulted about the change in care provision before it was put into place.

In contrast, Jean provides a useful example of the positive impact of continuity of care. Jean cared for her mother, who had a respiratory condition (COPD), at home. After having some initial difficulties in gaining access to support when her mother was discharged from hospital, Jean was very happy with the support that was provided by a particular formal carer, Karen. Karen visited Jean's mother twice a day, six days a week. Jean, her mother and Karen were able to build a trusting relationship over time and Jean and her mother were very happy with their arrangements. In the following excerpt, Jean describes how she took a week off work when Karen was on annual leave and was dismayed at the number of different carers that visited her mother during this period:

"P I had a week off [work] but I didn't tell [social services] I had a week off, I thought 'I'm gonna monitor this'. [pause] She had nine different carers [pause] within a seven day period..."

I How did she [mother] feel about that?

P Oh, she was dead uncomfortable⁴².” Jean

It is therefore evident that routine and continuity of care are very important to carers and patients in the home environment.

This presents a further challenge for good practice health and social care in the UK. Many carers who took part in this study emphasised their need for adequate and timely care and support from formal systems of care. The issue is challenging because carers who do gain access to such support may then be faced with further uncertainties regarding continuity of care.

The findings suggest that having many different carers visiting hinders the development of professional relationships between patients, family carers and formal carers, which carers describe as being so important. Furthermore, the findings also suggest that continuity of care is central to building good relationships within triadic care.

Ann also spoke of the importance of continuity of care in regards to district nurse visits:

“I think it could have been better. You know, I wouldn’t praise [pause] none of them. Everybody did their job, you know. But I think when it’s a different district nurse each day when we did get to the end.. Mum didn’t know who was coming in to [see] her. She was dying [and] they [district nurses] didn’t know what was going on. They were reading the card and [pause] it was hard. If it had been a continuation it might have been a little bit better.” Ann

The findings therefore suggest that carers consider continuity of care and building relationships of trust to be important in all aspects of community based health and social care.

In contrast to the previous examples, the following example demonstrates the importance of reliable and consistent care for patients with life limiting illness and their families. Elaine cared for her husband, who had Parkinson’s disease, at home. Unlike many other participants in the study she received monthly direct payments for care, enabling her to purchase care that was most suitable for her and her husband’s needs, rather than receiving a generic care package from social services. She found this to be much more satisfactory as she felt that she had a greater level of control, was able to get to know the carers and improved reliability and timing of visits.

⁴² Meaning ‘very’ uncomfortable

"P And the same ones came. Usually it was the same one at night er twice a week and then four times a week, the same one, and usually it was the same one in the day time. Once the night time one couldn't come and the day time one came, so erm, there was only, there were only a couple of times when a different er, a different one came, but she was also very good.

I So was it important to you and your husband to have the same person coming?

P Oh very important I think yes, yes

I Mm. Why was that?

P Erm, well just to get to know them and I had to show them round and where things where in the kitchen and, er and tell them about the medication, cos he was on a lot of er various types of medication... but they- I, you know told them what he had and went and they wrote it down"

Elaine

Furthermore, from a clinical perspective, a recent systematic review assessed the role of healthcare support workers (formal caregivers) in providing palliative and end of life care in the community (Herber & Johnston 2012). The review identified that close working with patients in community allowed formal carers and district nurses to identify deterioration over time (Herber & Johnston 2012). It is therefore sensible to suggest that a lack of continuity of care may prevent subtle changes in deterioration over time from being recognised, and in turn, fail to be communicated effectively to families. This again highlights the importance of continuity of care.

Direct payments were being piloted by a number of local governments during the fieldwork phase of this research. Consequently, only three participants in this study (Elaine, Pat and Catherine) received direct payments. Although only a limited number, each expressed their satisfaction with the direct payment system and were happier with the resulting services than the support that was arranged through social services. These findings suggest that this is an important factor in improving care and support for patients with life limiting illness and their family carers. Following the proposal outlined in The Carers' Strategy (2010), Direct payments were rolled out nationwide in 2011. These findings support those of a recent narrative review of literature which suggest that direct payments have the potential to empower service users and carers (Ottmann, Allen & Feldman 2013).

It may be useful to draw on sociological understandings of the 'stranger' (Schuetz 1944; Simmel 1950) to gain insight into carers' perceptions of formal carers in their homes. Both Schuetz (1944) and Simmel's (1908) notion of 'the stranger' adopt the perspective of the 'stranger' as an 'outsider' who attempts to gain acceptance into a group, which has established historical and cultural boundaries and understandings. However, the central concern of this study is how established group comes to accept the 'stranger' and gain their respect. In applying this concept to family caregiving, 'strangers' are formal carers who enter into a household in order to provide care and support in a professional capacity, whilst the 'established group' consists of patient, carer and other family or household members. The issue that has emerged from the data is that carers and patients are often uncomfortable in the presence of the 'strangers' who care for them in their homes. However, in contrast to the notion of the 'stranger' as presented by Schuetz and Simmel, the 'stranger' (formal carer) does not necessarily seek to gain acceptance from the household, as it is not their intention to become an established and long term member of the group (family/household). Furthermore, a formal carer enters the household as a paid professional and therefore does not present themselves as an 'equal' who seeks to gain acceptance, as described by the fore mentioned authors. Stone (2000) usefully asserts that care workers are 'at least initially strangers instead of intimate acquaintances or relatives' (p. 90). The author's use of 'initially' suggests that formal carers can indeed be accepted by the household over time. This again highlights the importance of continuity of care and patients, formal and informal carers building relationships over time.

It is useful to draw on the work of Canadian sociologist Anne Martin-Matthews, whose work focuses on home support for the elderly, to develop this argument. She describes how she re-evaluated her perspective on the subject following her mother's stroke, for which she required 30+ hours of support from formal carers at home. Her mother lived with her husband (Anne's father) and adult daughter (Anne's sister), and Anne's other sister lived nearby. Anne and her brother lived in other cities and, although they are in regular telephone contact, were unable to help in the day to day care of their mother (Martin-Matthews 2007). These family circumstances resonate with many of the participants in this study. In the following extract Martin-Matthews speaks about her interactions with her mother's formal carers and conversations with her siblings about their mother's care:

'I have had many private conversations with a succession of home support workers about their training, their motivations for employment in this sector, the challenges and rewards of their work and their concerns as women and as workers. I have listened to my mother grapple with how to approach these strangers who attend to her in the most intimate settings. I

have heard my father lament the loss of autonomy in his own home and its 'invasion' by a succession of women employed to care. I have spent countless hours talking with my sisters about how to manage the home care situation, the turnover of workers, their variation in abilities and the impact of their personalities on the home life experience of my parents and others in my family. I have also had the experience of making telephone calls to 'home', and having a home support worker answer the call. With this stranger (to me) then telling me about how *my* family members are doing, at such times I have thought to myself: who *is* this person?' [original emphasis] Martin-Matthews (2007, pp. 231-232)

It is interesting that Martin-Matthews refers to formal carers as 'strangers' several times in this excerpt and continues to do so throughout the paper, as it seems to support the argument I have presented in this section. Her use of language such as 'invasion' creates somewhat of an 'us' and 'them' dichotomy, which further emphasises the divisions between formal and informal support when there is a lack of continuity of care.

This personal experience enabled Martin-Matthews to reflect on her earlier research (1993, 1995 (Martin-Matthews & Campbell 1995), 2003). She asserted that this new lens enabled her to understand formal care at home to reveal 'issues of possession and control of the territory of home, giving rise to concerns about boundaries and spatial familiarity and attendant efforts to make sense of the 'stranger' in private places' and that 'the context and frame for these enquiries is the recognition of home care as situated at the intersections of the public and private spheres and of paid and unpaid labour (Martin-Matthews and Phillips, 2003)' (Martin-Matthews 2007, p. 232). However, the author's deliberate use of the term 'stranger' throughout the paper is somewhat problematic, as she does not attempt to define the term or draw on other literature around the 'stranger'. Martin-Matthews' references to formal carers as 'strangers' is perhaps symptomatic of her own view point on their presence in her parents' home, as implied in her earlier quote. Furthermore, although Martin-Matthews acknowledges that she purposefully positions herself 'within' the paper, based on her experiences, she fails to recognise her positioning of formal carers as 'strangers' in her writing.

Martin-Matthews presents an interesting observation regarding the literature on home care, commenting that 'home care has been crafted as if the word 'home' is merely a four-letter substitute for the words 'hospital or 'institution'' (2007, p. 233). She goes on to argue that relationships between formal carers, patients and families have different dynamics in the home care setting than in institutional settings (e.g. hospice, hospital, nursing home) (2007).

This is interesting as further analysis of the findings of the present study indicate that continuity of care was raised primarily in regards to care at home, with far fewer issues being raised about continuity of care in institutional care environments. This is an interesting finding, as it suggests that it is problematic to have 'strangers' in the home; that the home should be a safe, familiar and stable environment. It is possible that this issue is less apparent in other care settings as people may not have the same expectations, where it is feasible that that it is carers and patients that in fact become the 'the stranger' when entering a temporal place of care.

Martin-Mathews' secondary analysis focuses on two main themes; 'the meaning of space and place' in home care environments and 'the negotiation of relationships' with formal carers (2009 p235). Interestingly, these themes did not emerge from the analysis of interview data for this study. This may be because Martin-Mathews' research was conducted with current care recipients, their family members (including family carers) and the formal carers themselves. Her sample may have been in better health than the population interviewed for this study, all of which were carers of people with terminal illness. Furthermore, the role of formal carers in the Canadian study differed slightly from the role of formal carers in the UK. Canadian carers were described as 'home support workers' providing 'non-professional services' such as helping with personal care as well as other daily activities that facilitated independent living such light housework (p. 230). In the UK, formal carers provide personal care, but do not help with household tasks such as washing and cooking. It is possible that boundaries differ depending on the parameters of the professional role of formal carers.

Thinking about the provision of care at home and the interactions between formal and formal care, Martin Matthew's interestingly asserts that 'home' is situated 'at the nexus of the public and private spheres of paid and unpaid care' (2007, p. 234).

The following extract from an interview with Paul provides a further perspective on the discussion of formal carers as 'strangers' in the household. Paul cared for his wife at home. She had ovarian cancer.

"I was aware that there was a care package available, but we chose between us to just help each other and get through it rather than just, you know, rely on someone else, a 'stranger' if you like, coming through the house and help us." Paul

This extract demonstrates that some carers make a conscious and informed decision not to have home carers. Other participants also made this decision, however it is interesting that Paul partially attributes this to not wanting 'strangers' in their house.

The above discussion demonstrates the importance of continuity of care in the home. Findings indicate that formal carers are often viewed as 'strangers' and this issue may be compounded by a lack of continuity of care. The findings also demonstrate that the issue of formal carers as 'strangers' is evident across many cases. For some carers, such as Paul, this issue prevents them from accessing the care and support that may be available to them. For others, this issue surfaces because of the lack of continuity of care. The importance of continuity of care and 'getting to know someone' is an important aspect in considering the interactions between formal and informal systems of care, particularly in the home.

8.5.2 Hospital

Interestingly, the issue of continuity of care in the hospital environment raised different issues than those raised in the home-care environment, which raised issues are relationships and trust. In contrast to the home environment, issues of continuity of care in hospitals largely related to communication between family carers and health professionals. In some cases, changes in nursing staff and doctors led to mis-communication, carers having to give the same information numerous times to different members of staff and carers struggling to get updates on their relative's condition in hospital. It is interesting that issues of familiarity, trust and relationships was not given the same importance as in the home environment and suggests that interactions between formal and informal systems of care hold different meanings from carers' perspectives in the home and hospital care environments.

8.5.3 Hospice

Only one carer commented on issues relating to continuity of care in a hospice. Louise's husband had Parkinson's disease and was cared for in a hospice for the last six weeks of his life. In the following quote she explains how she felt hospice care was different to the care he had received in the hospital:

"It was more that erm the nurses knew him; [they] got to know him". Louise

When interpreting this quote within the context of the interview, Louise appears to be suggesting that it was comforting to her and her husband to build relationships with the hospice nurses. This was in contrast to their experience of care in the hospital, where they had experienced a lack of continuity of care.

The lack of data relating to continuity of care in hospice settings may suggest that issues such as those raised at home and in hospital were not problematic in hospice. However, this is difficult to verify due to the narrative rather than semi-structured nature of the interviews, where carers spoke about what was important to them personally, as opposed to responding to the interviewer's questions. Furthermore, as noted earlier, this thesis does not intend to

portray all hospice care in the UK as being without fault, but intends to accurately reflect the positive experiences of the participants who took part in this study.

To summarise, the findings of this section highlight the importance carers attribute to continuity of care, particularly in regards to care at home. The findings indicate that continuity of care is central to positive interactions between formal and informal systems of care. Although potentially challenging, providing continuity in care, particularly in the community, should be considered best practice by health and social care providers in the UK.

8.6 Uncertainty around pain and symptom management at the end of life

Findings indicated that there is considerable uncertainty surrounding medication and pain and symptom management at the end of life. This was particularly prevalent for carers who cared for a relative at home. Medication was discussed in the previous chapter in relation to feeling unprepared for the level of *responsibility* that was associated with medication management, throughout the illness trajectory, when caring for a relative with a life-limiting illness. In contrast, the discussion of medication in this chapter largely focuses on the impact of uncertainty around medication for family carers and will focus on carers perceptions of morphine in pain and symptom management at the end of life.

Uncertainty surrounding the expectations and use of morphine in end of life care had a significant impact on family carers in the study. It was evident that there were mixed views as well as confusion about the use of morphine in end of life care. Morphine may be used as a sedative (relieving anxiety and agitation) and as an analgesic (for treating pain and discomfort) (Seymour et al. 2002, p. 295). In many cases the word 'morphine' highlighted the seriousness of their relative's condition. For many carers, there was a great deal of ambiguity around the administration of morphine, as medical practitioners rarely explained its use to the family members of the patients they were treating. In the following extract, Janet talks about her experience of being given a prescription of morphine from the GP.

"[The doctor] gave me a prescription and he said it would be a good idea to go and get this prescription. He didn't say anything about it, "It'll ease the pain and I'll come out first thing tomorrow morning" and then he went and when I looked at the prescription it was morphine. And actually it wasn't- we had no conversation about "I'd like to give him morphine."

"I went for the morphine, in fact I wasn't sure whether to go for it and then I was sitting there thinking "Oh, is this, you know the end?", but then thinking "Well he said he'd come back tomorrow morning, I'll ask him tomorrow morning and see what he says...So I went and got the morphine in the end

and I gave it to my Dad and put him in bed and did all the things that I normally did and that was about 8 o'clock in the evening and I said to him would you like me to stay and er, in a way he could you know, "You go, you go".

"Erm that night I came home and by the time I got back 6 o'clock the next morning he was dead, he was just dead there in the bed. And he just had, you know the, he just had the two little... little spoons of morphine. I'm not saying they killed him cos I mean he was dying at the time." Jean

Jean's comments about her experience give an insight into the difficulties faced in interpreting the meaning of the doctor's prescription. It is evident that she was in some turmoil about collecting and administering the medication, as she had understood morphine to be a drug that was associated with the very end stage, although the doctor had not indicated this. She explained that she went about her daily routine of putting her father to bed and that things seemed normal, but that he died overnight.

Jean's quote demonstrates the close link between uncertainty and communication in the data. Some level of uncertainty is inevitable in the trajectory of terminal care, yet formal systems of care may be in the position to minimise uncertainty around pain and symptom management at the end of life through improved communication with families about morphine. This may include the circumstances it may be administered as well as its likely effects, for example. The appropriate time to have this discussion is debateable, but nevertheless, the findings of this study indicate that families need to be fully informed about morphine in order to reduce anxieties at an already stressful time.

In addition, a number of carers suggested that the administration of morphine hastened their relative's death. This issue of morphine hastening death is much debated in end of life care literature. Terminal sedation may be defined as 'the use of high doses of sedatives to relieve extremes of physical distress' (Quill & Byock 2000, p. 409). As Seymour et al. (2002) assert, whilst these authors describe terminal sedation as part of a clinician's duty of care; that 'withholding such treatment in certain circumstances would be inhumane' (Quill & Byock 2000, p. 409) others describe the practice as 'slow euthanasia' (Billings & Block 1996). It is important to acknowledge that morphine is likely to be administered to patients when they are in severe pain and/or very close to death. This highlights the importance of good communication around administering morphine at end of life, as carers' are often left with the perception that morphine was the cause of death, as the following quotes demonstrate:

"The Doctor must have been near and came up and increased the dose in the syringe, which I wasn't very happy about cos I didn't really want his mind clouded if he was dying. And they increased it a couple of times"

"It was all a bit... a bit sudden, a bit quick really. Maybe if they hadn't of increased the dose of morphine he would have lived a bit longer, but I don't know". Elaine

Similarly, Jean described her feelings about collecting a prescription for morphine for her mother:

"It's got to be one of the worst times of my life; going and getting it 'cause I felt like I was killing her, by getting the stuff." Jean

Robert was also uncertain about the use of morphine in his wife's care:

"And I got the district nurse and they fitted a little pump switch on her arm that was there all the time, and that was great for a few days, but it was knocking her out. That was slowly killing her. And I know what that's used for, despite what they say. And then that didn't work and she screamed out "Robert, Robert, I'm in pain", you know. And I rang for the nurse and she came, she looked at her and she just said "She's very ill you know", I said "I know", and she went "I'll give her an injection", "Ok", "And that'll ease the pain".

[pause]

Whatever she give her that killed her, because she was out the house, in her car, around the corner and was on that hill when I phoned her. Cos [daughter] shouted me "Dad, Dad!" and all this white stuff was coming out of her mouth.

I checked her pulse; there wasn't one. She wasn't breathing. And the district nurse, she came steaming back. She come in and she said "I'm afraid she's gone", and I said "Well I know that", you know? And I said "What was in that injection?", "Only morphine". It was something else but I'm not worried because she wanted to go. I couldn't bear to see her like she was". Robert

Robert believed that the medication that was administered to his wife (morphine) was responsible for her death. Robert presents an unusual case, as he effectively suggests that it

was not morphine that was given to his wife, but another substance which brought about her death. This is a serious accusation and one that Robert apparently believes to be true. He indicates that he was not worried, despite this belief, because it put an end to his wife's pain and suffering. It is plausible that if Robert had been better informed about the use of morphine in pain and symptom management at the end of life prior to this event, then he may have interpreted this event differently.

It is evident that the issue of morphine use in terminal care is a source of great uncertainty for family carers; presenting difficult decisions, guilt, worry and issues around euthanasia. The narratives presented here indicate that it was not the intention of the clinician to invoke terminal sedation, but rather that the sedation and death had occurred as a side effect of a high dose of morphine which was intended to relieve pain rather than induce sedation (Quill & Byock 2000). More information about end of life pain and symptom management, when given prior to this stage, may help family carers to feel better informed about the issues and likely outcomes of morphine and may help carers to make sense of the experience.

8.7 Feeling (un)prepared for the caregiving role

Carers frequently expressed that they felt unprepared for what their role would involve. In many cases this was largely due to having insufficient information about their relative's illness, how the illness was likely to progress and the possible implications of this for the caring for their relative. This was also noted in the 'carers as experts' section of the previous chapter; that carers' knowledge of the patient comes from within and is based on both their relationship with the person they are caring for and knowledge gained over time through experience. In stark contrast to this type of tacit knowledge is the explicit knowledge (Kontos & Naglie 2009) that can be taught or learned. It is useful to think about this in relation to the literature on caregivers needs.

These findings support those of Hudson, Aranda and McMurray (2002), who cite feeling unprepared for the caregiving role as a key finding of their research, which involved focus groups with current and bereaved caregivers palliative care nurses. This work led to the development of an education based intervention for family caregivers providing home-based palliative care (Hudson et al. 2008; Hudson et al. 2009; Hudson, Aranda & Hayman-White 2005). The final intervention addressed various dimensions of care, as summarised in Table 13. Hudson and colleagues also recognise the need to prepare and support careers of people who are in hospital in their caregiving role and are currently undergoing a programme of research to develop and test a suitable intervention for this population (Hudson et al. 2012a; Hudson et al. 2012b).

These interventions, targeted at a palliative population, were broadly found to be feasible, useful and acceptable to family caregivers. The evidence presented in this thesis suggests that many carers of people with a life-limiting illness experience uncertainty and a lack of preparedness for the role in the pre-end of life stage of illness, thus highlighting the importance of the timeliness of the intervention and how eligible carers would be identified (e.g. through community nursing registers, through GP practices etc).

It is interesting that feeling unprepared for the caregiving role is a finding that appears in both UK and Australian literature. This suggests that this is an important and possibly universal issue and priority should be given to addressing this within research, policy and practice.

Table 13: Title and objectives of education intervention sessions (adapted from Hudson et al. 2008, p. 272)

Session number	Session title	Objectives
1	What is involved in being a family caregiver?	(a) To provide education on the typical role of a caregiver in the palliative care context. (b) To outline the services available from the palliative care team, local doctor and other support services.
2	Caring for your relative/friend and taking care of yourself.	(a) To present key strategies relating to responding to a patient's physical and psychosocial issues. (b) Strategies to maintain family caregivers' well-being.
3	Caring for a person when death is approaching.	To deliver information about what to expect when: (a) Someone seems to be approaching death. (b) A person dies (including common emotional reactions). (c) Health professional supports (including bereavement).

8.8 Feeling (un)prepared for the future

For many family carers, health professionals are the gatekeepers to information about their family member's illness. Health professionals have the capacity to inform family members about the likely illness trajectory as well as the implications for their care. Having this

information may help carers to feel reassured and more confident in their role. Conversely, withholding information has an adverse effect and is linked to great uncertainty and associated anxieties. There are therefore clear links here between this aspect of uncertainty and the theme of communication, which is discussed in the next chapter. This is not surprising, as there is a body of literature that suggests that good communication between health and social care professionals and patient and their families is central to managing and reducing uncertainty (Brashers 2001; Hebert et al. 2009; Hines 2001; Waldrop, Milch & Skretny 2005).

Many participants in the study spoke about feeling unprepared for their relative's deterioration. This was often linked with a change in the needs of the patient or carer. The findings suggest that carers are unlikely to ask 'what is likely to happen as this illness progresses and what are the implications for care?', nor was this information freely offered by clinicians. Rather, both care and information from formal systems of care appear to be offered on a reactive rather than proactive basis i.e. information is offered on a need to know basis or is offered in dribs and drabs rather than in advance.

Ann cared for her mother who had a neurological condition (PSP⁴³). She had not been informed that people with this condition often experience difficulty feeding themselves and have difficulty swallowing, but later found out from a specialist nurse that these were common problems with the condition. It is the retrospective realisation that the anxiety could have been alleviated if she had known in advance that this was common with the condition that led to Ann having negative feelings about the circumstances. She eloquently described that being a carer was '*going in blind*' in regards to the lack of information she and her family had to prepare themselves for what may come as a result of her mother's condition. Similar examples were reported across the data set, providing further evidence of areas where formal systems of care could be improved in order to improve the lives of both family carers and their relatives.

Ann went on to explain that she felt that it was only when a specialist neurological nurse became involved in their case that she was able to gain the information she needed to care for her mother properly and gain adequate information about what to expect as her health deteriorated and what to do. This situation was echoed by many carers in this study. Many of these carers felt that the health services should have provided more support in this area and should have informed them earlier in the illness trajectory about the likely progression of illness. Family carers also felt that they found out by chance, through the internet or other personal resources rather than this being standard practice.

⁴³ Progressive Supranuclear Palsy

"It was just lack of information really. I don't know how people are...given an explanation as to terminal disease or an illness. I don't know how GPs do it. I don't know- do they sit down with you and say 'This is how it's going to be'? Does somebody who specialised in that say 'This is what to expect. This is what's going to happen?' I've never experienced it before; I don't know.

I think if we'd have been given...I wouldn't say a counselling session, but some kind of a meeting or something with somebody in a professional capacity. Maybe the GP or...I don't know. There seemed to be a big chunk missing...of information. And we had to source the information ourselves. But I don't know whether that- does that happen with people with cancer or are they counselled more. Or do people give them information? Do they hold their hand all the way through? We didn't have- and I know they do, because you hear of other people and the care they have. But with this, we felt quite isolated really.

I You said that you felt there was 'a chunk of information missing'?

P Yeah. Right from diagnosis really to the end. I felt that if we hadn't- or if I hadn't of accessed the [PSP charity], then we would have been...I don't know, high and dry really. Just left without...'Just deal with that today and deal with that today and do your best'. Is that what you're expected to do, or should we have expected more help? I don't know [pause] I don't know'.

Ann

The above quote gives an insight into the reflections and on-going uncertainty that Ann felt about the lack of information about her mother's illness. She identifies how important she felt that this kind of information is, yet remained unsure about how this information is communicated and who should deliver it. The fact that she asserts that she believes people with cancer and their families get better access to information and support is also interesting and implies that support from health services and associated agencies provide differing levels of support to people depending on their condition, however, the findings from this study suggest that uncertainty regarding the likely progression of the illness is not disease specific, but is experienced by carers across disease.

Paul provides an example of the positive impact that feeling better informed can have. Speaking about his wife's admission to a hospice he described how the health professionals involved in his wife's care helped to prepare them for the future:

“They were absolutely fantastic, you know, we were speaking to Doctors there and they were saying “Well look...”, she’d started suffering from sickness and things, “we’ll bring you in and we’ll start to treat the symptoms that you have”... and started to gently prepare us for what was coming basically.” Paul

“But we would always discuss what was said, and what they prepared us for, and what was to come and erm, as I say, I was very happy with every aspect of it.” Paul

Paul indicates that the approach to communication about the likely progression of his wife’s illness was helpful in preparing them both for what was to come. It is worth noting that he refers to ‘prepared us’ (plural), rather than ‘prepared me’ (singular) indicating the value this had to him and his wife. Furthermore, the second extract indicates that the impact of this was that they were able to discuss things together. Paul indicates his happiness with the care at the hospice and in both cases airs his satisfaction with the hospice closely to them preparing them for what may come. It is not surprising that this example of the positive impact appropriate communication can have is from a hospice, as hospices are experts in communicating with patients and their families regarding end of life issues. This suggests that sensitive communication regarding possible short and long term outcomes can have a positive impact on the experiences of carers and patients. It should also be noted that other carers and patients may not want to know details of how their illness is likely to progress, or an expected prognosis, preferring to live day by day. This highlights that how much or how little a person wants to know about their condition is unique to that person and that these wishes should be respected. Nevertheless, the findings suggest that many carers would benefit if this issue was raised by health professionals (and perhaps revisited on occasion during the illness trajectory); empowering carers and patients to make a choice.

Retaining the focus on end of life and preparedness for death, the findings suggest that those who cared for a relative at home at end of life experienced the most uncertainty. Many lay people, including carers, do not have an in depth knowledge of the biological process of death and dying. Many participants in the study reflected on their apprehension about not knowing what to expect in the days and hours leading up to their relative’s death.

Rachel cared for her sister, who had ovarian cancer. She explained that she would have liked someone to talk her through the likely process of dying, so that she would be more prepared and have had an idea of what to expect.

"I would've liked someone to explain to me what happens in the last week or last few days of life, cos I didn't know what to expect and it was quite upsetting, and I would have been prepared more...I would have been able to deal with it better if someone had actually explained what had happened, what would happen in the last few days of life [pause] cos I didn't know what to expect." Rachel

Rachel asserts that she 'may have been able to deal with it better' if the process had been explained to her in advance by a health professional. In a further example, Linda demonstrates how other aspects are also important in dealing with uncertainty around death.

"...other signs and symptoms that death are imminent are, you know, some get gurgles in the throat or make more, you know, he didn't get the 'death rattle'⁴⁴ but got some horrible sounding things similar to a rattle, somebody to talk to about those things, what to expect. I knew it 'cause I'd been through it with my mum and my dad but um...it's different when it's your partner um.... you know somebody to talk you through things..." Linda

In this case Linda suggests that she knows what to expect regarding the likely physical process of death, as she has previous experience of this with her parents. Her quote suggests that she would have found some comfort in being reassured and being emotionally supported by health care professionals at this time. These findings are consistent with the literature around preparing for death, which is commonly referred to as 'preparedness' in the literature on this topic. In a study assessing key factors in preparing carers for the death of a loved one, Hebert et al. (2009) found that regardless of other life experiences of ill health and death, all cares expressed uncertainty around aspects of medical (principally the need for information), practical (e.g. regarding wills and finances), psychosocial (e.g. family dynamics) and religion/spirituality. Most notably, the authors found that communication between formal and informal systems of care and the patient was quintessential in preparing family carers for the death of a relative (p. 8). They argue that 'clear, consistent and reliable communication between all parties (HCPs [physicians, nurses, social workers, clergy, etc.], the patient, and other family members) involved at end of life was of primary importance for preparing caregivers. Inconsistent or ambiguous messages could make preparation more difficult' (ibid). Furthermore, they found that family carers placed importance on 'what was said' as well as 'how it was said' and as such were important factors in managing carers' uncertainty at end of life (ibid).

⁴⁴ The National Cancer Institute assert that a 'rattle occurs when saliva or other fluids build up in the throat and airways in a patient who is too weak to clear the throat' (National Cancer Institute 2013).

Whilst Paul's quote provides an example of the positive effects of preparedness, the extracts from Rachel and Linda demonstrate the negative impact of a lack of preparedness around death. Paul's experience was uncharacteristic of the experiences of other participants in this study; the majority of participants in the study felt that the lack of information they received from health professionals throughout the illness trajectory had a significantly negative impact on their role as a family carer and may have impacted on the care they were able to provide for their relative. This issue arose in the majority of interviews and was not disease specific (*it is difficult to provide evidence in a short quote to illustrate this finding because this issue was so widespread*). Rather than being disease specific, preparedness for the end of life as well as preparedness for symptoms and deterioration associated with an illness appears to be closely related to the relationship that exists between the carer and the health professional; carers who had a good relationship with the person or people involved in their relatives care appear to have had these important conversations which lead to preparedness. This was evident, for example, amongst participants where a specialist nurse was involved with their care and/or where continuity of care was reported as being good.

Additionally, preparedness at the end of life was closely linked to the involvement of palliative care teams, both in the community, in hospital and in hospices. This is an important finding; narratives tell us about experiences that hold personal importance to participants. This finding can be translated to health and social care practice as it not only highlights the importance of continuity of care in terms of the relationships that are built between health and social care professionals, patients and carers, but also suggests that preparedness is closely linked with professional relationships.

Hebert et al. (2009) suggest that preparedness has three dimensions; cognitive; affective; and behavioural. The 'cognitive' dimension refers to knowledge and information regarding the medical, practical, psychological and spiritual aspects described above. The 'affective' dimension refers to emotionally preparing for a person's death. Finally, the 'behavioural' dimension of preparedness refers to practical aspects such as planning a funeral and other 'practical' aspects that must be undertaken when a person dies (Hebert et al. 2009, p. 8). Importantly, they argue that all individuals' experience of preparedness will involve cognitive, affective and behavioural dimensions and that these dimensions will be weighted differently for each individual. The preceding quotes provide evidence to support Herbert *et al*'s (2009) theory; Rachel felt that information on the biological process of death would have been beneficial, whilst Linda valued emotional support and reassurance, or 'affective' dimension as the most heavily weighted dimension.

Feeling unprepared for the future is therefore evident at end of life, yet carers felt particularly unprepared in the pre-end of life stage of the illness trajectory. This is particularly disruptive when patients have a hospital stay for example and are discharged home with carers not knowing that their circumstances have changed in a way that impacts their support needs.

“and also when we left the hospital more information about what to expect.... They just said “well we’re not going to transfuse him, you know, give him blood or things that are not doing any good”. Ok, well tell me what, please explain you know, what happens next....it’s about that not knowing, not having enough knowledge about what happens next and when you’ve got that sort of communication and you’ve got nobody coming in to tell you anything and when they did come they didn’t explain anything anyway because they didn’t know what was wrong with [husband] half of them it....it’s a mess.” Linda

This also raises the question of whether all people with life limiting illness should have a specialist or dedicated nurse; a person with whom they can build a relationship with, who gets to know the person and their family, who gets to know their case in detail and who provides a direct point of contact for patients and their families.

There is evidence that the government has recognised such issues in the NHS and is working towards change; in July 2013 the Health Secretary, Jeremy Hunt, unveiled plans to provide elderly patients with a ‘named clinician’ upon their discharge from hospital. He said

“Most people now leave hospital with long-term conditions which need to be supported and managed at home. So the challenge today is to provide integrated, co-ordinated, out of hospital care. Something where the NHS, with our tradition of family doctors and primary care, could lead the world...But to do that we need to know that there is a clinician accountable for vulnerable older people in the community, just as there is a consultant responsible for them in hospital...They should be named so that patients, families and carers all know where the buck stops.”

Jeremy Hunt, Health Secretary (BBC News 2013)

Furthermore, Mr Hunt also noted that care aimed at managing long-term conditions such as diabetes, chronic obstructive pulmonary disease and heart disease ‘need radically different models’ to those currently in place within the NHS and that patients with such conditions may also benefit from the ‘named clinician’ proposal (BBC News 2013). This is an important step towards achieving continuity of care and adds validity to the findings presented in this thesis.

8.9 Employment and financial uncertainty

An estimated 3 million people in the UK are currently in full or part time employment in addition to their role as a carer (Cross-Government Publication 2010, p. 42). The government estimates that 'three in five people will become carers at some stage in their lives, the majority during their working lives' (ibid). Furthermore, the issue is set to become increasingly poignant in the near future as the government estimates that by 2017 the number of people requiring care and support will outweigh the number of working age family members (ibid). Such evidence highlights the significance of employment matters around informal caring within the UK. The current government recognises the urgency of this issue and is currently taking steps to prepare for it. For example, 'Recognised, valued and supported; Next steps for the carers strategy' (2010) identified financial and employment issues as key issues and outlines the government's intentions to tackle the issues. Similarly, the Equality Act (2010) supports family carers by legislating against discrimination based on one's caring responsibilities, which includes discrimination in the workplace.

Employment and financial uncertainty were important issues for family carers in this study. This is relevant to the research question as a carer's financial and/or employment situation may affect their ability to provide care and support for their relative. Furthermore, it is vital to discuss these issues here as it provides a context in which the other issues presented in this thesis should be considered.

8.9.1 Employment

Emanuel et al. (2000) report that there is often a significant financial burden associated with caring for a family member with a terminal illness. The authors of the US based study note the cost of health care, as well as other costs such as transport, home adaptations and costs around personal care. Financial aspects of care such as advice about and access to benefits and issues around employment are relevant to the research question as formal systems of care, such as social services, and other formal infrastructures such as employers play a key role in supporting family carers. Issues surrounding employment and other financial aspects of caring were prevalent within the data collected for this research study. Many participants adapted their working life in order to care for a family member with a life limiting illness. Findings from this study indicate that employers' attitudes and policies towards supporting employees with caring responsibilities differ vastly. Whilst some employers were flexible and accommodating to their employees' circumstances, others were not, which caused family carers a great deal of uncertainty, anxiety and worry.

A number of employers were supportive and accommodating to their employees' circumstances; making provisions for reduced hours, extended paid or unpaid leave, or in

some cases, early retirement. Paul, for example, had had a long career in the police force and felt very well supported by his employers when his wife was diagnosed with terminal cancer. He had considered taking early retirement in order to care for her at home but was advised to take compassionate leave so that he could return to work after his wife's death, if he wished to.

"I just got in touch with work and I said that you know, "I want to take early retirement to be with me wife if it's only gonna be months". So they were very good and turned around and said "Well, if that's the case, if you leave us we can't look after you, but if you stay with us we'll do the best we can". So I continued for about 17 months on full pay and on compassionate leave, so I was very lucky... very lucky." Paul

Paul felt 'very lucky' to have supportive employers, which suggests that he recognised that this is not necessarily standard practice amongst all employers. Being supported by his employers to take compassionate leave had a positive impact on Paul. He was in regular contact with his employers regarding his circumstances and felt supported as a carer.

Flexibility and compassion towards employees with caring responsibilities was also seen in the private sector. Barry, for example, worked for a delivery company and was granted paid leave for three months so that he could care for his terminally ill mother, who also had cancer.

"Work were very good. My line manager wasn't so good, but I went above his head and I offered to leave work and not get paid, but my mum was adamant, even towards the end; 'No'. So I went to my above manager and he said 'No problem at all. You only have one mum', he said. So he said 'You take as long as it takes you'. So I was off work for three months. I got paid." Barry

Similarly to Paul, the above quote suggests that the period of paid leave was granted at the discretion of a compassionate manager rather than being company policy⁴⁵.

Other employers were much less accommodating of their employees' needs. Jean, for example, worked within the NHS yet was unable to gain approval to adjust her working hours to care for her mother who had a respiratory condition (COPD). She explained:

⁴⁵ It should also be noted that there is no intention to imply that there is an association with employers being more sympathetic to carers of people with cancer than carers of people with other illnesses. The quotes used here are purely illustrative of different approaches by employers.

"I was trying to hold my job down; in fact I ended up on the sick and I ended up with a warning because I was trying to look after my mum. I tried to reduce my hours but they wouldn't let me [pause] and I work for the NHS." Jean

Although Jean and her mother lived together, Jean also worked full time and, as she described above, was unable to gain approval from her employer to adapt her working hours to help care for her mother. She describes the difficult situation they were faced with and suggests that because she lived with her mother they were not considered as a priority for an assessment from the social worker at the time that the hospital wanted to discharge her mother.

Jean went on to explain the impact of this on their circumstances:

"We had to bed block⁴⁶ for a week in order for me to get a social worker... If we'd have come home when she was ready to come home I wouldn't have got a social worker...cos trying to get on that system is horrendous. And she was crying "I want to come home" [inaudible] "but mum if I bring you home now, we're not gonna get nothing; we're not gonna get a social worker, carers..." I said "I can't....", I said "I'm either gonna have to pack up my job" and [she said] "You're not doing that" I said "Well, we need to get the ball rolling on something"...."

The drastic measures that Jean felt necessary to employ in order to get adequate support set up at home reflect some of the problems and difficult situations faced by family carers. Jean felt that she had no option but to take this action due to the lack of flexibility from her employers regarding her situation. It demonstrates the knock on effect of this, causing a great deal of distress to both carer and patient, not to mention the money that 'bed blocking' costs the NHS in cases such as this.

Jean went on to describe several further attempts to address the issue with her employers:

"You know, I don't like people seeing me cry but I was crying when I said that 'Please, I need help. I don't want to lose my job. Can't I just do three days a week?', 'No, [it] doesn't work like that' and I'm thinking, 'Well stuff you'....and that's why in the end I did think well 'I'm going on the sick'".
Jean

⁴⁶ Meaning refusing to be discharged home from hospital.

This quote demonstrates the deep-seated frustration that Jean felt about her situation. Additionally, the issues that Jean raises in regards to not wanting to have to give up her job, the longer term financial implications of this and being left with no option but to 'go on the sick' deeply resounds with the issues carers reported in 'The Carers' Strategy' (2010) and are issues that the government are keen to address.

The lack of flexibility shown by Jean's employers made Jean's circumstances particularly difficult. Jean explained:

"I was her sole carer, especially of an evening... Once I was in from work I never moved. I was getting no sleep, no nothing and in the end I...I was....I was crying, I was that tired." Jean

This quote demonstrates the difficult situation Jean was in as she continued to struggle juggling her work responsibilities on top of her caring responsibilities.

"but I don't think they quite appreciated what I was going through. Cause I'd say the last.... six months....was hell and that's when I thought I need to try and....I didn't want to walk out my job, although I would have done in the end, because I thought if my mum's not here I'm going to need that job more than ever, financially as well as keeping myself sane...and I did go in on numerous occasions and....to say 'Look, is there any way'... I went 'Look, she's not going to be here much longer, is there any way I can just do three days a week?' I said 'I'm at the end of my tether now' I said 'I'm physically and emotionally drained'... 'No'." Jean

Jean's story demonstrates the difficult position she was placed in, whereby she wanted to keep her job but also needed to care for her mother. Her employer's inflexible attitude significantly added to Jean's stress, to the point where she had to take several months off work with stress related illness to look after herself and her mother. Going 'on the sick' was a route also taken by other carers in the study (such as Graeme) whose employers would not make provisions to accommodate for their employees' circumstances.

Stories such as Jean's demonstrate some of the difficulties carers find themselves in when employment commitments clash with family and caring commitments. The policy document 'Recognised, valued and supported; next steps for the carers strategy' dedicates a significant proportion to addressing financial and employment issues. Indeed, the policy recognises that "carers often feel forced to give up work to care" (2010, p. 6). It identifies flexible working arrangements as having the potential to make the most significant difference to working

carers. The document indicates that the government is in consultation with other agencies about introducing both legislative and non-legislative measures to support both employees and employers (see pages 17 and 18 of The Carers' Strategy, 2010). Additionally, the government is consulting with the charity 'Employers for Carers'⁴⁷, as well as other organisations, to encourage and support businesses to offer flexible working arrangements for employees who have family caring responsibilities. Their research presents a strong business case for flexible working, claiming that supporting their employees in this way 'attracts and retains staff; reduces stress; reduces recruitment and training costs; increases resilience and productivity; reduces sick leave; improves service delivery; produces cost savings; improves people management; and increases staff morale' (Employers for Carers 2009). The emergent picture therefore is that flexible working arrangements and understanding employers benefits both employers and employees.

Flexibility around employment, as well as financial status and family situations all impact on the capacity of family members to care for their relatives. There were numerous instances in this study where the primary carer felt that they needed additional support from family members to care for their relative. In some cases, juggling work with caring was possible, largely due the support of other family members and formal carers. However other relatives, particularly those who lived far away, were financially restricted as to how much time they could take off work to come to stay. As noted in the previous chapter, it is common for immediate family members to live in different cities, counties or even countries to one another.

Issues around employment and the consequent financial impacts are therefore crucial issues for family carers. The government's concept of the 'big society' and policies embracing this rhetoric must do more than what is already being done in order for flexible working arrangements or temporary leave for carers to become common place within UK employment practice. 'Recognised, valued and supported: Next steps for the Carers Strategy' highlights the importance of employment issues around informal care. The 'Employers for Carers forum' provides evidence from employers as to how and why accommodating carers' needs can be beneficial to employers and employees alike.

8.9.2 State benefits

A mixed picture emerged from the data regarding participants being informed about state benefits. The data suggests that cancer patients and their family carers have a number of opportunities to be informed about benefits they may be entitled to. Patients and families may

⁴⁷ Employers for Carers works with small, medium and large businesses (such as BT and British Gas) to support carers

receive information about their benefit entitlement immediately after diagnosis, with Macmillan nurses, social workers or members of staff at a hospice broaching further discussions at different stages of the illness trajectory.

In the following quote, Paul provides an example of how cancer patients may be informed about benefits. Paul and his wife were informed of such entitlements by the staff at his local hospice, where his wife attended day care.

“But again you know, [Hospice] explained everything with regards to the benefits, what we may be entitled to erm, all the facilities that we, you know we could have at home, they made sure where there for us.” Paul

The following extract provides an example of the procedure for informing cancer patients and their relatives about the possible financial implications of their illness (although it is unclear whether this is the case for all cancer patients). Pauline relays her experience of receiving information about their benefit entitlement immediately after receiving a cancer diagnosis in hospital.

“The nurse came and sat where he [consultant] had been sitting so the three of us were still opposite and she said ‘The first thing you need to do is claim Disability Living Allowance’. So I’m sort of totally bewildered by now because I thought, ‘What’s that got to do with his cancer?’ you know. So she said, ‘I’ll give you the number to ring’, and she was busy writing down the number to ring. And she said, ‘If you get on to them and get your doctor to fill in this form...then you will get Disability Living Allowance. It’s a hundred pound[s] a week and that will really help you with all your hospital visits; if you need to get taxis and things like that and if you need extra heating’. And I thought ‘She’s not telling me anything that I want to know, you know?.’” Pauline

The above quote provides an example of this hospital’s procedural approach to communicating information about benefit entitlements, of which it could be argued there are both positive and negative implications. In terms of positive implications, this structured approach ensures that all patients receive information regarding state benefits and that no one is missed out. However, on the negative side, this quote raises important questions about the appropriateness of the timing of this conversation. Pauline comments that she felt ‘bewildered’ and thought ‘what has this got to do with his cancer?’. The last sentence of the extract also implies that receiving information on state benefits was not her top priority at that

particular moment and there were more important things that she needed to know. My understanding of the meaning of this narrative is that Pauline and her husband needed some time to take in the news of the diagnosis. By contrast, the feel of the conversation she relays suggests that in this case the nurse takes control of the conversation, giving information that is important from her perspective. Pauline implies that this is not what is most important to her at that moment. Insights such as this have important implications for practice; although it is important for patients to receive adequate and timely information about financial aspects of care in order to minimise financial uncertainty later on, it is clear that existing procedures may not be appropriate for someone who has just received a cancer diagnosis.

By contrast, the picture for non-cancer patients is much more inconsistent. Non-cancer patients in the sample received information about funding and benefits from a range of sources, seemingly by chance, such as through encounters with funeral directors, oxygen delivery people, charities such as Age Concern and through word of mouth. The exception to this was Rosemary, who found out about her benefit entitlement through her husband's respiratory nurse, who arranged for a referral for an assessment through social services. The timing of receiving this information was therefore inevitably also inconsistent.

Helen cared for her husband who had a respiratory condition (COPD). She explained:

"Nobody actually sat down with me and said "you can claim this, this, this and this". We didn't get the carers allowance, which I should have got. Erm, that wasn't mentioned at all." Helen

Helen went on to explain how she received a benefits assessment, by chance, from the housing association, who happened to be visiting all tenants in the area. She explained that, through the housing association assessment, she found out that she was entitled to an extra £25 a week. Helen had amongst the lowest Townsend scores of the sample and had had to pay for various aids to improve her husband's quality of life. She had previously explained that it had been difficult to finance these aids.

8.9.3 Means testing for care and support, state benefits, and aids and adaptations

For the majority of participants, financial support was an important issue in regards to improving the quality of life of the person being cared for. Means testing for selected state benefits, aids and adaptations, and assistance from formal caregivers was a source of uncertainty, anger and frustration for many family carers. The NHS Choices website 'Carers Direct' states that means tested benefits are available for people who have 'limited income and capital (savings, investments and property that's not your main home)' (NHS Choices 2012). Limits are set by the government and assessed by a paper or online forms which

carers complete, which documents their financial status. Many participants (particularly those with more economic resources, as indicated by Townsend Scores) felt that they had paid into 'the system' for many years and felt that they should therefore be entitled to financial assistance to draw on these services when needed, rather than spending their life savings. Furthermore, those who were entitled to benefits also found the system difficult to negotiate.

"I was struggling and we tried to get help from social services, but the usual story- erm...When you've saved all your life; put away a few bob, you don't get nothing, you know". Robert

A number of family carers also expressed that they were not informed and therefore not prepared for the benefits of the person they were caring for to terminate on the date of their death, nor were they prepared to be billed retrospectively for benefit payments that were made to the cared for person after their death. Being unprepared for benefits ceasing following a person's death is likely to be a universal problem rather than a problem related specifically to people with life limiting illness and their families, but nevertheless should be recognised as a source of anxiety at what is already a difficult time for bereaved family carers.

"And erm even after he died nobody sort of said to me "you're entitled to these benefits". And it was two weeks off my 60th birthday and nobody told me I could've claimed widows pension. Erm and what we had to do was his money was stopped from the day he died, so I had to go on income support for myself and I got a grand total of £5 a week... to live on. Erm plus the, yeah it was £5 per week and then when I got my old age pension then erm my money went back up and they turned round to me then erm "you can put in for pension credit" and I said "right" and put in for pension credit and then they came to me and said "you're too old now for erm widows pension but what we can do is get you a grant" and they got me £2,000 lump sum to put me over". Helen

By contrast, one participant, Paul, was informed by the undertaker that he may be entitled to a source of state benefits because of his wife's age. He explained:

"Even after [wife] had passed away the undertaker happened to say to us that you know there is, in actual fact, because [wife] was so young there is a bereavement benefit that you can apply for. So when you go to register the death, there's a form that you receive... 'Are you entitled, are you interested in any benefits you may be entitled to?.and just tick the box and

then, it was them that made me aware of the bereavement benefit that I was entitled to, I didn't know anything about. And it was a case of you know, there was a lump sum paid into my account within weeks of me filling in this form and then I was entitled to a benefit for 12 months after she died, which was incredible.” Paul

Although finding out about this benefit was positive for Paul, it again highlights the inconsistencies that exist in providing family carers with information on financial entitlements.

8.10 Summary

This chapter has demonstrated the prevalence of uncertainty and the importance of reassurance in the experiences for carers of people with a life-limiting illness. The chapter has demonstrated the strong links between uncertainty, worry and anxiety, and conversely, the positive impact that reassurance can have. As emphasised throughout the chapter there are opportunities, throughout the illness trajectory, for many of the causes of stress, anxiety and worry to be reduced.

There is a wealth of literature around ‘caregiver burden’ or the ‘burden of care’. However, I would like to raise the suggestion that in many cases this ‘burden’ arises from the inadequacies of formal systems of care that should be there to support family caregivers in their role. The narratives of carers in this study have highlighted a number of problematic areas in health and social care. Throughout the chapter I have drawn on carers’ experiences to draw out elements of practice which are likely to have a significant impact in minimising uncertainty in the caring experience and increasing the positive effects that may be attributed to reassurance.

It is useful to refer back to the discussion of Mishel’s theory of uncertainty at the beginning of the chapter; ‘uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately’ (Mishel 1984, cited in Mishel 1988, p. 225). Mishel’s quote has proved to be a useful reference point in discussions about uncertainty in illness. Although Mishel’s definition of uncertainty is concerned with patients, this chapter provides evidence to suggest that the definition may be extended to the experience of family caregivers of people with life limiting illnesses, as various aspects of uncertainty have been demonstrated throughout the chapter.

Furthermore, Mishel states that uncertainty is ‘not considered to be a dreaded or a desired state until the implications of the uncertainty are determined’ (Mishel 1990, p. 256) and that attaching meaning to an issue or event is an on-going process which may change over time. In this way, events which are initially perceived as negative may, over time, be perceived as

positive and vice versa (Mishel 1990, p. 258). This study found no evidence to support this statement. Rather, the findings from this study indicate that uncertainty is an inherently negative experience for family caregivers, where inadequate and disjointed support from formal systems of care is the main contributor to caregiver burden. In order to minimise the negative impact of uncertainty, this chapter has argued that refocusing efforts back into basic principles of good care and ensuring this is achieved would impact positively on the experiences of patients with life limiting illness and their family carers.

Furthermore, this chapter has also demonstrated the vast differences in the care and support received by carers. Whilst a large number of studies have assessed the needs of carers and patients with cancer, as well as interventions to meet these perceived needs, findings from this study suggest that carers of people with cancer and their relatives receive vastly varying levels of care and support, as do other disease groups. This is an interesting finding, and again points towards the need for care to be improved at a basic level, across the board, to reduce uncertainty and improve access to consistent, good quality care and support.

Finally, the evidence presented in this chapter supports the findings of recent government reports which acknowledge the importance of financial and employment issues experienced by family carers.

Chapter 9

Findings III: Communication I

“Good communication underpins all elements of care and if we can get this right at the end of life, it will make us better communicators all round.”

Claire Henry, Director, National End of Life Care Programme (NEoLCP),

cited in ‘talking about end of life care: right conversations, right people, right time’ (NHS 2011).

Communication is central to the examination of how systems of formal and informal care interact to meet the needs of carers and patients and emerged as key theme in this study. The previous chapter identified that uncertainty was closely linked with communication; this chapter expands on this idea and explore it in further detail.

The communication theme is presented in two parts; ‘Communication I’ addresses verbal and non-verbal communication in interactions between systems of formal and informal care. ‘Communication II’ specifically addresses the concept of kindness and compassion in care, as this emerged as a particularly important aspect of care and support and was a very important part of carers’ perceptions of interactions between themselves, their relative and health professionals.

‘Communication I’ begins by examining effective verbal communication at different times in the illness trajectory and in different care settings. This is followed by a discussion on carers’ need for information about their relative’s illness and will argue that current NHS policies on doctor/patient confidentiality can (in some cases) act as a barrier and may prevent family carers from gaining sufficient information about their relative’s illness. Findings also indicate that carers need adequate information on the likely progression of their relative’s illness at the point of diagnosis and throughout pre-end of life care. The discussion then highlights end of life conversations between patients, family caregivers and health professionals as a key issue in communication in end of life care. The chapter concludes with a discussion of power dynamics in verbal and non-verbal communication in different healthcare settings. This is discussed with reference to ‘cultural health capital’ (Shim 2010b) as a theoretical perspective.

9.1 The need for information

The previous chapter highlighted the importance of reducing uncertainty for carers and patients. The findings indicate that a lack of forthcoming information was a great source of stress and anxiety for family carers, who described their ‘battle’ for information. This section

argues that the key ways to achieve this is through improved, effective and timely communication with families about their relative's illness.

Pauline cared for her husband, who had lung cancer (primary). He also had secondary brain metastases⁴⁸, which heavily impeded his physical abilities. Pauline, like many other carers in this study, felt that she needed more up front information from the hospital about her husband's condition.

"Erm– definitely more information from the hospital– definitely more...Erm just more information instead of us having to push and ask and worry all the time." Pauline

The following quote from Catherine is particularly powerful; she sums up the difficulties she faced trying to navigate the medicalised world. Her evaluation is particularly significant as it echoes comments made by many other carers in the study. Catherine cared for her husband who had been diagnosed with colon cancer and multiple sclerosis.

"Erm, [someone] who can just sit alongside you at times and talk through things with you about what's happening during the process; you don't get any of that at all, and I think that's one of the things I would have benefited from being able to ask the questions, but also being guided, because what you don't know you don't know... Sometimes you don't know what questions to ask because you don't know that they're there to ask."
Catherine

Catherine asserts the difficulty of knowing what questions to ask health professionals, particularly early in the illness trajectory. She reflects that having the opportunity to speak with someone 'during the process' would have been beneficial.

Similarly, Linda felt that there was a lack of information throughout her husband's illness. Here she speaks of her experiences of hospital care and home care:

"And also when we left the hospital; more information about what to expect. They just said 'well we're not going to transfuse him, you know, give him blood or things that are not doing any good'. 'Okay well tell me what; please explain you know, what happens next'. It's about that not knowing, not having enough knowledge about what happens next and when you've got that sort of communication and you've got nobody coming in to tell you

⁴⁸ Metastases occur when cancer cells travel from the primary source to another part of the body. Metastases may also be referred to as a 'secondary' cancer.

anything and when they did come they didn't explain anything anyway because they didn't know what was wrong with [my husband] half of them.....it's a mess". Linda

This quote gives the reader an insight into the confusion and frustration that family caregivers can experience. The data suggests that multi-disciplinary teams and lack of continuity of care contribute to the fragmentation of services and poor communication between teams. This problem is recognised in the recent report 'Caring for our future' (Department of Health 2012a), which proposes a new 'person-centred' model of care to help tackle problems such as this. More recently, the NHS Commissioning Board approached National Voices to produce a narrative around integrated or 'co-ordinated' care (Acton 2013). The King's Fund, the Nuffield Trust and the NHS Future Forum are united in recognising the importance of a 'person-centred' model of care (ibid). Linda felt frustrated that she was frequently required to give information about her husband's illness to carers and district nurses who visited, as lack of continuity of care was a problem. Although co-ordination of care *between* services is addressed in 'caring for our future' (Department of Health 2012a), the issue that Linda raises is concerned with co-ordination of care *within* services. This issue does not appear to be recognised within the white paper.

Linda went on to explain the need for greater clarification about the support available at home:

"I think again an explanation of exactly what's on hand and what you can ask for....a detailed explanation of what's available and who provides it, because um.... the Macmillan nurses said 'well if you need some help you've only got to ask', you know, who do you ask... in that circle? Is it the Macmillan palliative care nurse? Is it the district nurse? Is it your GP? Nothing is made clear.

I just felt that within that circle, this side didn't know what that side was doing and vice versa". Linda

Linda highlights the problem of not knowing who to turn to for different aspects of support. This problem may be related to the issue of role ambiguity, which was outlined in the roles and relationships chapter. Linda, like many other participants in this study, was unclear about who to turn to for advice and support. Examples such as this highlight the need for clear information about the roles of professionals in multi-disciplinary teams.

There is little evidence to suggest that cancer patients and their family caregivers receive more or better information than other patient groups. Rather, information needs appear to be more easily met in cases where a specialist nurse is involved in care provision (as highlighted in the previous chapter). Examples of specialist nurse involvement from this study include support from Macmillan nurses, respiratory nurses, neurological nurses, cardiac nurses and Parkinson's nurses highlight the value of specialised support for family caregivers. It is useful to draw on a case study to demonstrate this further. Ann cared for her mother, who had Progressive Supranuclear Palsy (PSP), along with her sister and step-father. She spoke of the on-going difficulties she and her family faced in getting information and support about her mother's illness, particularly around knowing how the illness was likely to progress and how to meet her continually changing needs. Throughout the interview she spoke of the difficulty in accessing the 'right' care for her mother; she gave examples of help coming too late and receiving conflicting advice from health professionals. Ann also explained about the various health care professionals that were involved in her mother's care:

"The GP put us in touch with the lady from the hospice and she came. The social workers were coming...a rapid response team were allocated to her which consisted of- I think it was a physio [physiotherapist], a speech therapist, a dietician, all of which I think, without any disrespect, did any- they were no use to my mum".

"I thought they were going to be somebody- [fast- voice up and down to emphasise] wonderful people that were going to come and just relieve us and help us. But they weren't they were...[shrugs] [pause]...They were just people who came in". Ann

Ann indicates that she felt frustrated that when she finally gained access to a service that they couldn't provide the support or information she felt that she and her family needed. Ann's situation improved greatly when she contacted a charity that support people with this condition and their families. The charity put her in touch with a specialist nurse:

"The help from the PSP [charity and nurse] helped to fill that gap. They were fantastic. And just with practical things really, and emotional- the way you're feeling and the way mum would be feeling. Everything [specialist nurse] said to me happened. It was as if it was already written...[having this information] did seem to ease, a little bit, the horrible situation that we were in". Ann

Field notes from Ann's interview also confirmed the importance of the involvement of a specialist nurse: *After the interview finished, Ann talked to me further about how much the support from [the specialist nurse] meant to her.* These feelings were strongly reiterated by other participants who had access to a specialist nurse. Where carers had previously felt lost and confused by the health and social care system and frustrated at the lack of information, involvement from a specialist nurse often meant that care became co-ordinated and tailored to a person's needs; family carers were given as much information as possible about caring for their relative and help in understanding the illness and how it was likely to progress. The general consensus of participants who were supported by a specialist nurse was that having this support was one of the most important aspects of their caring experience. The positive impact of the reassurance gained from having a specialist nurse should therefore not be underestimated and could be considered best practice in care and support for people with life-limiting illness and their family caregivers in the community.

Evidence from this study suggests that specialist nurses are not routinely assigned to patients with life-limiting illnesses. Rather, carers are put in touch with specialist nurses through the 'back door', such as through charities or word of mouth. This study suggests that support from specialist nurses should be considered as an integral part of providing health and social care to people with life limiting illnesses and their family caregivers. A recommendation therefore is that people with life-limiting illnesses should be routinely referred to such services early on in the illness trajectory.

9.2 Doctor/patient confidentiality can become a barrier to family caregivers gaining the information they need

Current NHS policy protects the privacy and confidentiality of patients in their care. However, findings of this study indicate that this can become a barrier to effective communication with family carers. This is problematic when considering the interaction between systems of formal and informal care.

According to the NHS Choices website, the NHS Constitution 'sets out in one place what patients, staff and the public can expect from the NHS in England' (NHS Choices 2013d). This includes statements about the rights of patients and the duties of staff to adhere to guidance on confidentiality. The following information on confidentiality is adapted from the NHS Constitution (NHS 2012).

Difficulties around confidentiality did not emerge as an issue amongst spousal carers, but were problematic for adult children caring for a parent. Such difficulties occurred with gaining information from their parent's GP and also in the hospital environment. This is interesting because it suggests that carers' access to information about their relative is dependent on

their relationship rather being accepted as a person's main carer. This is problematic because all carers are likely to need the same level of information in order to care for their relative, regardless of their relationship to the person they are caring for. This is also problematic because the definition of a person's 'carer' in healthcare policies does not distinguish between caring relationships.

Table 14: Patient Rights (adapted from NHS constitution pg 45)

Right	What this means for patients
<p>"You have the right to privacy and confidentiality and to expect the NHS to keep your confidential information safe and secure."</p>	<p>NHS staff will respect your right to privacy and confidentiality. All the personal information on you and about any treatment you receive from healthcare organisations is confidential. NHS bodies must comply with 'data protection principles', which include, subject to certain exceptions, personal information being held or disclosed only with the consent of the individual concerned.</p> <p>There is a senior clinician in every large NHS organisation, termed a 'Caldicott Guardian', who oversees and advises on confidentiality matters and safeguards the interests of patients.</p>

Table 15: Duty of Care (adapted from NHS constitution pg 107)

Duty	What this means in practice
<p>"You have a duty to protect the confidentiality of personal information that you hold unless to do so would put anyone at risk of significant harm".</p>	<p>Disciplinary action may be taken by the employer against workers who breach the data protection policies.</p>

For example, Janet found it very difficult to obtain information about her father's condition from both the GP and from members of staff at the hospital. Janet was a qualified counsellor and therefore understood the importance of doctor/patient confidentiality. She commented that:

"Confidentiality is a really important thing to me, I really respect [that] it's one of the key things... but nearer the end it became an obstacle, you know...I think it was one of the things that got in the way of them being able to give me any sort of information". Janet

Ann also experienced difficulty in gaining information about her mother's condition from the GP:

"In the end I went to mum's GP and I made an appointment, because they were our doctors as well. And he was very, very good, and very professional, and didn't discuss you know, mum's condition with me, up to a point, where in the end I had to push him and say 'Look, I need some help here'". Ann

This quote is interesting as it demonstrates that Ann understands that doctors are bound by confidentiality, but explains that this became problematic and impacted on her as her mother's carer.

In cases such as this health professionals are placed in an understandably difficult position. NHS policy and guidelines on confidentiality stipulate the importance of doctor/patient confidentiality (see Tables 14 and 15), however, in cases where a relative is a person's main carer then the carer needs information about their relative's condition in order to make provisions to care for them properly and also to prepare themselves for what is likely to come in the future.

Janet commented that it was difficult to obtain information about her father's condition if she presented herself as her father's 'daughter' to hospital staff, but that it was much easier when she presented herself as her father's 'carer'. She also commented that formal carers (such as care home staff) were privy to more information than she was and she felt that this was wrong.

"That, I think that left me feeling like, 'well yeah you're a carer but... so what?' Erm, it seemed like when there was a carer with a patient and the carer had a uniform on from a nursing home, that that carer seemed to be

more privy to information than I was...[for] the last 18 months or so I started to emphasise that I was the carer, but I'd been his carer all along." Janet

This issue is problematic when we consider that family carers rarely identify themselves as their relative's 'carer', particularly earlier on in the illness trajectory (as discussed in the roles and relationships chapter).

9.3 'Dancing in the dark': the lack of information on the condition and the likely progression of the illness at diagnosis and in pre-end of life care

Family carers identified that a lack of detailed information regarding their relative's condition, the likely progression of the illness and where to find help and support were fundamental problems experienced across the board by many participants in this study. This caused a great deal of uncertainty, worry and anxiety for family carers.

Many carers sought information about the likely progression of their relative's illness. Pauline cared for her husband who had lung cancer with brain metastases. The brain metastases caused frequent seizures, which had a significant impact on her husband's motor skills and his ability to communicate. Pauline received excellent support from her GP whilst caring for her husband at home:

"I have this very, very good GP who really was my greatest support in those eight months. In fact I don't think I would have been able to cope really without her – she was our best point of contact". Pauline

However, she explained how she struggled to obtain adequate information later in her husband's illness. She felt that more information should have been offered to her by health professionals rather than having to personally take the responsibility to seek out information:

"I had to search all the time for that information. And ask. And I was constantly told that every cancer patient is different and that they didn't know, they didn't know what was going to happen to him. Every cancer journey is a different one – which I suppose is true. So I did really feel we were dancing in the dark a little bit, for help and advice". Pauline

This quote demonstrates carers' appreciation and understanding regarding patients' differing illness trajectories and life expectancies. However, it is clear that carers, such as Pauline, need to obtain some measure of their relative's place in the illness trajectory and what the near future is likely to hold. Examples such as this also demonstrate the interrelated themes of this study; in this case uncertainty and communication are unquestionably interlinked.

Janet's father suffered from COPD and emphysema. He also had a heart condition. Janet drew on her experience of liaising with her husband's cardiac nurse to demonstrate the differences between having and not having adequate information about her father's illness.

"[If] they'd tell him something about his heart and I didn't quite understand and I said to her 'I haven't quite grasped what you've said. Can you tell me what does that really mean about the functioning of his heart?' and she actually did. She went in to great lengths; she drew a picture and went into great lengths about telling us in comparison to someone who hasn't got a heart condition. And wow it didn't half make a difference to both of us".

Janet

Janet went on to describe how this information helped her and her father to understand his condition better. She described how, six months after the appointment with the cardiac nurse, he had experienced breathlessness and chest pain whilst gardening. He also had a fall around the same. The information provided by the cardiac nurse helped Janet and her father to understand these episodes and to break up tasks so that he was not putting his heart under too much strain. She explained:

"Once he erm had that information he didn't do that anymore, he got up gradually and slowly and he didn't have those falls. So it made a big difference, it really did whereas with his breathing, he just couldn't grasp... why, he said it right up til the very end, 'why can't I breathe?' It's like he just couldn't understand. And I do think that was something to do with the information [inaudible], I believe that". Janet

Janet explained that the cardiac nurse was able to give her father comprehensive advice about his condition. Janet evaluated the positive impact that feeling informed had on her and her father; *"So information helped, to live day to day. [pause] It did; it helped to live day to day"*. By comparison, Janet explained how she and her father felt lost, confused and frustrated over the lack of information he had about his respiratory condition.

Helen also drew on contrasting experiences to emphasise the impact of uncertainty brought about by a lack of enough information about symptoms related to her husband's respiratory condition.

"We went ahead and bought an automatic bed because I thought the back would help him with his breathing, but the amount of nights he sat on the edge of the bed trying to get his breath and knowing he couldn't because

he said when he lay down he felt as if he was drowning; he couldn't get his breath at all. Nobody told us that side of it, nobody warned us. If they'd have warned us I would have expected it and I would have done something about it. We weren't warned about that side of it.

And really and truly speaking, when I was first diagnosed as diabetic, and he was, we went to a seminar and the diabetic people were [slowly to emphasise] absolutely brilliant; they went over the diet rules, what exercises we should be doing erm how to cope with it. And COPD, there was nothing, do you know what I mean? It was as if, "oh you've got COPD, don't worry about it". Helen

Helen also had problems with her health and felt that on discharge from the hospital that she was not given enough information about her husband's condition to adequately prepare her for his return home. Helen's Townsend score was the lowest of the sample, indicating considerable social deprivation, yet she purchased a new bed which she believed may help to ease her husband's COPD. Helen was totally unprepared for the symptoms that would follow with COPD and felt aggrieved about this. She compared the lack of information about COPD against her own experience of feeling well informed about her own diabetes via the diabetes clinic. She emphasised that she felt that COPD was not taken seriously and that families were not being adequately supported to deal with symptoms and symptom management.

Rachel, like many other carers in this study, used the internet to help fill the gap in information left by the health services. Rachel, cared for sister who had been diagnosed with ovarian cancer.

"I got all my information from the internet". Rachel

The internet may be a useful resource for information when used *in addition* to advice and support from health professionals, but it is problematic if the internet becomes the primary or sole source of information. It is concerning that carers, such as Rachel, felt that they had to seek out information about their relative's illness for themselves, as this indicates that in some cases, the current healthcare system are not meeting carers' needs. Assessing the credibility or trustworthiness of information on internet sites can be difficult. A further problematic issue is that lay people may make medical judgements without discussing issues with a health professional. Further problems also arise when we consider that not all people have access to the internet, or have the knowledge or skills to know how to use it. Ann assisted her step father in caring for her mother who had PSP. She explained:

“My mum’s husband, our stepfather, was told that it was a very rare disease, they didn’t have an awful lot of information they could tell him. But they told a sixty-five year old man to look on the website and they wrote a website down to look on the website. He didn’t have a computer or anything”.

“I think it [information about the illness] should have come from the hospital really, considering it’s such a rare disease. I don’t think you should be left with the website written down on a piece of paper and told to go away and look at that. [pause] Totally unacceptable”. Ann

In a further example, Pauline explained how she found help and support through the internet.

“I found a very helpful line- [name of organisation], which I actually found just on the internet – with myself looking. Which was a premium phone-line. They were smashing and you could ring them up day or night – I think it was manned twenty-four hours by specially-trained cancer nurses. And I think that would have been absolutely excellent for anybody else. I found that really late on; I found that possibly round about July, maybe June. But that again was searching myself on the internet”. Pauline

Pauline emphasises her role in finding and accessing this telephone support, as she felt that support from the health services did not meet her needs. It is also concerning that she was paying for a premium rate service to meet her support needs, as adequate support did not appear to be available through the NHS. Her use of a 24 hour premium rate phone line also indicates that she was not aware of local out of hours services that may have been able to offer support.

The narratives of carers in this study demonstrate the uncertainty and anxiety that the unknown causes families, whilst also providing evidence on the positive impact of effective conversations with families about the progression of their relative’s illness.

This section provides evidence of poor communication between health professionals, patients and their family carers. One participant’s quote that she was left ‘dancing in the dark’ in attempting to obtain adequate information about her relative’s condition was representative of many participants in this study. This quote highlights the importance of information and preparedness in pre-end of phase of the illness trajectory. The following section addresses how these issues remain significant at the end of life.

9.4 The value of end of life discussions for family carers

Carers' needs for information about their relative's illness also included being made aware of their relative's stage of the illness trajectory, particularly at the end of life. In this study carers frequently commented that caring for their relative was firmly situated in the present and getting by 'day by day'. This made it difficult for carers to recognise deterioration at home, as deterioration often happened slowly over time. In comparison, other carers supported their relative through frequent crises and hospital admissions, and indicated that they were not made aware of the seriousness of their relative's condition upon their final hospital admission. Examples of such illness trajectories are demonstrated in Figure 1.

Research has shown that a lack of preparedness for the death of a relative is linked with depression, anxiety and complicated grief (Hebert, Dang & Schulz 2006). Whilst health professionals cannot prepare family carers for a sudden or unexpected death, health professionals can play a vital part, regardless of place of care, in helping carers to understand what happens when a person is approaching death from a life limiting illness.

Communication about what happens to a person as they approach death falls under many categories in the literature in this area. The term 'end of life conversations' is used hereafter in order to describe communication around death to family caregivers. Although the term 'conversation' implies an exchange between health professionals and carers, findings from this study indicate that a short, clear message can be effective in preparing carers for their relative's death. The key point here is that carers should be given the option about whether they would like to discuss their relative's condition, the likely illness trajectory and any other appropriate aspect of death and dying.

In the following quote Catherine talks about preparedness for the transition between pre-end of life and palliative care.

"From all the various disciplines that should be involved with the carer and the patient, so that when you actually reach the stage of palliative care being recommended you actually have a pretty good idea of what that means erm, and you're not left with erm a lack of knowledge, or questions and erm, that the environment in which you actually then are, er, your loved one is going to die is appropriate and so on and so forth. So there's something about putting a marker down erm that leads, you know, twelve months before er to palliative care. Er, that it's not kind of a, a sudden experience that happens." Catherine

This quote provides an important example of the need for better communication about a person's deterioration in the transition between pre-end of life and palliative care. Catherine explains that she thinks this is important so that it does not come as a shock when palliative or end of life care is finally required.

Having explained the importance of end of life discussions and the impact this can have on family caregivers, the place of care will now be examined in more detail.

Communication with family members about death was perceived to be particularly poor in the hospital environment. The data suggests that discussions around end of life care pathways, palliative care and death, for example, were often ambiguous or implied. This meant that carers often misunderstood communication around death and dying. It appears that some professionals are therefore failing to communicate effectively with families at this important time, in a way that family members gain a true understanding of what is being said. Karen, for example, reflected on a number of instances that she now realises were clues about her husband's impending death, but she was not able to interpret them as such at the time. In the following quote Karen recounts a conversation she had with a nurse after staying overnight with her husband in the hospital. Karen's husband had emphysema and COPD. He was admitted to hospital, where he later died.

"[I said] 'I'll have to go home'; I wanted a shower... [and] the nurse said 'you will come back, won't you?', so I said 'course I'll come back'. She said 'don't be long'. [Loudly] Those things didn't click when she said 'you won't be long?', you know?, I should have thought to myself, 'oh she thinks he's going to die any minute', you know". Karen

It is important to acknowledge here that it can be difficult for health care professionals to predict how long the end of life stage will last and that some people do die unexpectedly from life limiting illnesses. However, the evidence presented in this study demonstrates the importance of family caregivers (and indeed other close relatives) being told gently but *clearly*, where death is predictable, that their relative is nearing the end of their life.

It is useful to draw upon a further example from the data in order to further develop this point. In the following extract Rachel explains that she would have felt more prepared for her sister's death if a health professional had spoken directly to her in the last few days of her sister's life. Rachel cared for her sister, who had ovarian cancer. She later died in a hospice.

“I would have liked someone to explain to me what happens in the last week or last few days of life, cos I didn’t know what to expect and it was quite upsetting, and I would have been prepared more”. Rachel

Rachel clearly demonstrates the importance of clear communication around death and dying. This example is interesting as it demonstrates that although hospice care usually constitutes best practice, that this is not the case all of time.

The majority of cases from palliative and hospice care provide evidence of clear, empathetic and effective communication with families regarding their relative’s condition, which was welcomed by relatives. It is useful to revisit Pauline’s story to demonstrate this. Pauline’s husband was admitted to hospital following a series of seizures connected to brain metastases. He was later transferred to a specialist palliative care ward within the hospital.

“So he was transferred to palliative care; feeding was stopped and we spoke to the palliative care consultant, (name); a very nice man and he explained what would happen. And he said ‘we’re just really taking everything away now from (Husband)’ he said ‘I know that sounds really, really cruel. We’re taking away antibiotics, we’re taking away the seizure medication because we’re at the stage now where prolonging his life would be exceptionally cruel to him. He’s now got no quality of life any more about what’s happening to him. We’ll put him on a morphine drip to make sure that he’s not in any pain. The last thing he’ll lose is hearing so keep talking to him all the time. You know, keep telling him you love him. You can stay with him and you can come and go as often as you want to or you can stay with him twenty-four hours”. Pauline

Pauline reflected:

“Everything was explained and we were made to feel very, very important and that (Husband) was very, very important as well”. Pauline

Pauline’s description of the end of life conversation she had with the consultant in the palliative care ward provides a detailed account of good practice. The detail and tone in which she recounts this experience suggests that this conversation had an important and lasting effect on Pauline. These quotes demonstrate the positive impact that appropriate and effective communication can have at this important time.

Paul provides further evidence of the positive impact of clear communication about the end of life. Paul’s wife had ovarian cancer and received hospice care:

"The nurses, sometimes after they'd visited [wife] took me to one side and they'd say 'you do realise what's going to happen' and everything else 'and we're here if you want to talk to us'. And you know, up to the very end of the Friday when they took her in when she was unconscious as soon as I went into the Hospice erm, a Doctor took me to one side and he said, 'right, this is what [wife's] going through at the present time...this is the medication that she's under and I can tell you now'- in the nicest possible way 'that she's not going to make the weekend'". Paul

Good communication between Paul, his wife and the hospice staff enabled Paul and his wife to have important conversations before her death:

"[My wife and I] would always discuss what was said, and what they prepared us for, and what was to come and erm, as I say, I was very happy with every aspect of it". Paul

These exemplars from hospice care are largely representative of others' experiences of receiving good communication at the end of life. In contrast, a mixed picture emerged of communication of end of life in the home care environment. For some, district nurses engaged in clear end of life discussions, effectively communicating when a carer's relative approached death.

Harry was an elderly gentleman and cared for his wife at home, where she later died. Harry's wife was also elderly and had been diagnosed with lung cancer. The district nurses talked to Harry and his family about his wife's deteriorating condition and explained that she was approaching death. He explained:

"I usually wash her and put cream on her and er, they [district nurses] said, 'Oh, we need to check the bed sores' and then er...my son came around and my two daughters, and I went into the garden and two nurses came out the back and I said 'Oh, you can go in, the family's in' and they said 'We need to talk to you', so I came in and they told us then: 'She's in the later stages now, can't do nothing for her and she'll only last 72 hours. We've known them to last longer' she said 'but I think within 72 hours'... She lasted er, a week, and it was in the early hours of the following Monday er, when she died". Harry

Although Harry did not explain explicitly what this meant to him it is possible to interpret that he felt somewhat content with this knowledge and that this facilitated preparedness for his

wife's death. The clear yet empathetic approach of the district nurses in informing Harry and his family about his wife's deterioration was effective as he is able to clearly recall the conversation and he and his family were able to prepare themselves for her death.

In contrast, Linda experienced what she considered to be poor and ineffective communication about death and dying from the district nurses supporting her and her husband at home. Linda and her husband were approaching their retirement when he was diagnosed with Leukaemia⁴⁹. Here she talks about the difficulties in engaging her husband in conversations about end of life.

"Maybe she [Macmillan nurse] was trying to get at it when she said on that one occasion 'Is there anything worrying you?' and [my husband] didn't take the bit as it were. I think be more up front; I know you've got to judge the patient but we both were pretty sensible people, you know. If they were more open and don't hedge round it. You know, say um.... 'You are in a terminal phase, we're not sure how much longer you've got', um 'Do you need to talk through things with [wife]?' or 'Have you spoken about your fears?', or 'Is there anything you want to say to your wife and family....um....before it's too late?' I felt that people were dancing around the situation we were in".

Linda revisited this point later in her narrative:

"Somebody to talk about things, to help us um-.yeah to help us to talk about it because whilst we both acknowledged that [husband] was dying, it would have helped if somebody had enabled us both to talk more openly. We could have- I mean he used to say 'I haven't got long' and I used to say 'don't talk like that' I'd say 'you're only poorly, none of us know how long you've got' and I- I was shutting him down so I think it would have been better if um- if somebody had been able to help us to be more open and talk about everything."

In this example Linda recalls an occasion where a Macmillan nurse attempted to engage her husband in a conversation about end of life, but that this had been unsuccessful. She revisited this point later in her narrative, but interestingly changed the focus from her husband to herself as she is able to reflect that she sometimes 'shut him down' from opening up. Linda was particularly tearful when talking about this issue. The emotion that was present within her narrative suggests that this had a lasting impact on her.

⁴⁹ Cancer of the blood.

The importance of this issue was shared by Carol, who cared for her adult son at home (he was thirty years old). At the end of her narrative I asked if there was anything that she felt could have been improved. She responded:

"I would have liked to have had more help in how to talk about death to someone young. Surely there must be someone in Macmillan that could have helped to say "that is normal", how they feel or... "do it this way" [long pause]. Carol

It is interesting that Carol raised this as the most important area that could have been improved, which again reflects the importance of this issue for some caregivers.

It is somewhat surprising that there were so few examples in the study where participants spoke about having end of life conversations with the person they were caring for; it is interesting that this did not emerge more frequently in the data, as it would be relevant to all people with a life-limiting illness. However, because this was not a question in a semi-structured interview for example, it is not possible to ascertain other carers' experiences of this in order to make further comment on this from the perspective of family caregivers.

Existing literature on end of life conversations, from the perspective of district nurses and formal caregivers, indicates that healthcare professionals actively avoid discussing death and dying with patients and their families (Herber & Johnston 2012; Miskella & Avis 1998). Furthermore, Miskella and Avis (1998) identified that formal carers in nursing homes found it difficult to talk about death and dying and often employed strategies such as focusing on task orientated care in order to avoid such conversations. The literature in this area is underdeveloped and it is unclear whether formal carers or other health professionals employ similar strategies to avoid talking about death and dying with relatives of a person with a life-limiting illness.

Linda went on to explain the difficulty in seeing a person's deterioration when spending every day with them. An extended quote is used here in order to sufficiently illustrate the difficulties faced by some family caregivers.

"Because you're looking after somebody for so long and caring for them twenty four seven the reality doesn't become a reality if you know what I mean?"

The district nurse and the GP had been in that morning...she's a lovely girl the district nurse...she was a Sister and she just said to me '[Linda], have you spoken to [the Priest]? I think you need to ask [the Priest] in' and I

laughed, 'Didn't I tell you he's coming tomorrow?' He comes every Thursday. She said 'No, I think you need to ring him and see if he'll come in'. And I was switched off, I was stupid, I thought 'Yeah I'll give him a ring' and it wasn't hitting home, you know, if she'd have said to me 'Do you understand what I'm saying to you?'

"I would have liked somebody to have said he's very poorly, his pulse is weak or....or whatever so that I could have sat up there continually rather than bob up and down".

"The link here I'm trying to make is if people had have been a little bit more explicit, 'Look he's getting weaker, we don't think he's going to last beyond a week', I'd have sat up there and actually slept [beside him]. I mean, I could have spent more time [with him] and then again you see, it's so difficult because then you balance, well.... you need that break from the room but I do have that....that niggle that in the last week particularly, I wished I'd been up there all the time". Linda

Linda's narrative provides a detailed insight into her experience and subsequent reflections. It is interesting that she makes suggestions on how communication could be improved and indicates that she has often reflected on this issue. Linda also indicates that she feels a sense of guilt and regret that she did not stay at her husband's side in the last days of his life. Furthermore, her quote *'I was stupid'* indicates that she blames herself for not interpreting the situation differently. The final sentences of this exemplar indicate that Linda still struggles with this; that she knows she needed a break from physically being in the room with her husband but also the sense of regret and perhaps guilt that she feels. I think what she is trying to explain, through terms such as *'dancing around the situation'*, is her frustration that health professionals did not make the end of life explicitly clear to her and as such she did not feel fully informed in order to make her own decisions. This, evidently, has had a lasting impact.

Other participants who cared for their relative at home were not able to discuss end of life conversations as explicitly. As discussed in earlier findings chapters, a number of family carers had distressing experiences of their relative's death, which occurred shortly after their being given morphine by health care professionals. This led carers to believe that morphine hastened death and, as acknowledged earlier, the association between morphine and death was not discussed with family members, resulting in a lasting uncertainty around the death of their relative and a lack of preparedness for death. Not only was the association between

morphine and death not discussed with family carers, but conversations around death were also missing. This also contributed to carers' not feeling prepared for their relative's death.

Continuity of care may also play an important role in identifying when a person is deteriorating and approaching the end of life, as a lack of continuity in care means that district nurses and other formal carers are not able to form a picture of a person's deterioration over time. This issue is addressed in a recent systematic review which assessed the role of healthcare support workers (formal caregivers) in providing palliative and end of life care in the community (Herber & Johnston 2012). The review identified that close working with patients in community allowed formal carers and district nurses to identify deterioration over time (Herber & Johnston 2012). It is therefore sensible to suggest that a lack of continuity of care would prevent subtle changes in deterioration over time from being recognised and in turn fail to be communicated effectively to families.

Furthermore, it could be argued that a lack of continuity of care at home may result in the failure of practitioners to take responsibility of engaging in discussions with patients and carers about end of life. It is plausible to consider that a lack of continuity of care may also mean that district nurses may find it difficult to broach the subject death with a person that they don't know well. Time constraints may also play a significant factor in accounting for the lack of end of life discussions discussed in the data set. This is anecdotal and speculative; further research is clearly needed in this area in order to better understand the difficulties around end of life discussions in end of life care at home in order to make recommendations on how improvements may be made in this area.

There were several examples in the data where participants were cared for in hospital at the end of life, with some involvement of hospital based palliative care teams. Whilst the evidence presented in this thesis has largely identified good practice in hospice care and palliative care wards, communication failed to be effective despite involvement of hospital based palliative care teams. Claire, for example, cared for her husband at home until he was admitted to hospital towards the end of his life, where he later died. Claire was generally very happy with the majority of the care she and her husband received in hospital, but reflected that communication in the time approaching death could have been improved.

"I think the palliative care team could have been more direct, a little bit more- yeah a little bit more direct in saying "Look, we don't expect [husband] to live very much longer. You do realise?... You know, they didn't even say 'I think you ought to get the family in' or anything". Claire

It should be noted that only a small number of participants in this study stipulated that they received support from palliative care teams whilst in hospital (not including those that were in a specific palliative care ward of a hospital). Therefore it is not possible to suggest that this is representative of others' experiences. Further research is needed in this area in order to understand staff training in end of life conversations and how this achieved in practice in different care environments.

Although some of the data presented here implies that end of conversations were inadequate, it is important to recognise that death can be difficult to predict, particularly in non-cancer (see Figure 1). Furthermore, it is interesting that there were no examples from the data where participants *didn't* want to know about their relative's prognosis. This is likely to be connected to the narrative approach to interviewing adopted in this study, where participants speak about what was important to them rather than the interviewer posing questions.

All four interviews where carers' relatives were cared for in a nursing home at the end of life were carefully analysed for communication about death and dying. Marie's elderly mother was cared for in a nursing home due to a neurological condition. Marie was disappointed that the nursing staff had not raised that they had observed some unusual characteristics, which Marie later found out were symptomatic of end stage disease. This indicates that the nursing home staff did not have the knowledge or experience to associate these symptoms with end of life and were therefore did not communicate effectively with Marie.

"It was as if she'd forgotten how to swallow, so you'd try and get her to swallow and um- I know it must have- I'm sure it went through my brother's mind that- he, I'm sure, thought that she was doing it deliberately; trying to starve herself because she'd had enough... And found out afterwards about the symptom, it's- apparently um [inaudible] store food in the pockets in their mouth and that's what they do." Marie

Although a small body of literature exists around the skills and experiences of nursing home staff caring for residents at the end of life (see for example Miskella & Avis 1998; Oliver, Porock & Oliver 2006), UK based research relating to the experiences of family caregivers of those who have died in a nursing home is limited. Further research is needed in this area in order to better understand such circumstances. It would also be useful to compare the perspectives of nursing home staff and family carers on this matter.

Having considered the impact of the presence or absence of effective discussions around death and dying within the context of different care environments, the evidence suggests that

the hospice approach to engaging relatives and, where appropriate, patients in end of life conversations could be considered as best practice. Furthermore, it is important to consider why focused end of life conversations are more prevalent in hospice environments rather than home, hospital or nursing home care settings; it is possible that this occurs because people are usually referred to hospices as in-patients when it is clear that they are dying.

This issue may be problematic because a great deal of verbal and non-verbal communication is *interpreted*; health professionals may or may not have used the appropriate language to signal that a person was approaching death. The data provides evidence that communication is often unclear; that although health professionals can be credited with attempting to broach issues around death with family caregivers, that this communication often fails to get the message across to be sufficiently understood by family members. The evidence suggests that indicating or implying that a person's condition is deteriorating does not go far enough, as it may or may not have been understood and taken on board by family members. Clear but empathetic end of life discussions are essential to improving communication in this area and the examples from hospice practice above provide excellent exemplars of how this kind of communication can be delivered and the positive impact it has on family caregivers.

The recent NHS publication 'Talking about end of life care: right conversations, right people, right time' (NHS 2011) asserts that practitioners may avoid such conversations for a number of reasons, including not wanting to get too close emotionally to patients (Heaven & Maguire 1997; Higginson 1993), a belief that death signifies a 'failure' in a healthcare system which is focused on diagnosis and curative treatment and ambivalence surrounding when a person is likely to die (NHS 2011, pp. 5-6). The report highlights the need for improved communication around death and asserts that training should be provided for health practitioners across all healthcare environments, whether that be in acute or community settings.

9.5 Optimising clinical interactions: considering the role of cultural health capital

The majority of participants in this study had upper region Townsend scores, indicating that participants had a sound financial standing, or 'economic capital', such as savings and other financial assets, such as owning a house (Bourdieu [1983] 1986). Bourdieu's notion of 'cultural capital' (Bourdieu [1983] 1986) is also useful here, as this may further contribute to economic capital. Cultural capital may can be summarised as 'non-material goods such as educational credentials, types of knowledge and expertise, verbal skills, and aesthetic preferences that can be converted into economic capital' (Appelrouth & Edles 2012, p. 656).

Shim (2010b) draws on Bourdieu's notion of cultural capital to develop the concept of 'cultural health capital' (CHC). CHC refers to factors which impact on patient/professional interactions, such as norms attitudes, behaviours, non-verbal and verbal styles of

communication, for example, which ‘may result in optimal health care relationships’ (p. 1). Shim notes that CHC exists in relation to patient-provider communication and interactions but notes that this does not extend to other aspects of health care, such as access to services or quality of services (p. 12). It is for this reason that CHC is useful to apply to a discussion of communication in this chapter, but is not appropriate to be used as a theoretical perspective throughout the thesis.

The majority of the participants in this sample were what Bourdieu would describe as rich in ‘economic’ and ‘cultural’ capital. This is demonstrable by Townsend scores (see Table 12 demographic information) and anecdotal information on living circumstances, education and employment (many people were in or had retired from professional jobs). In contrast to Shim’s theory, data from this study suggests that even those who possess ample CHC struggle to navigate the complex systems in health and social care in the UK. This leads us to question that if this relatively privileged demographic experience such a broad range of difficulties, then what are the likely experiences of people with less social and cultural capital?

The concept of cultural health capital is relevant to the research question, as it highlights the importance of interactions between systems of formal and informal care and factors contributing to the success of these interactions. Shim (2010b) argues that cultural health capital offers a framework by which to understand patient-clinician interactions:

‘Cultural health capital provides a way to understand how features of patient-provider interactions- such as interpersonal rapport, exchange of information, empathy and trust- are accomplished or undone, based upon the repertoire of specialised cultural resources the patients bring to the health care encounter, in combination with providers’ fostering of and receptiveness of those resources. That is, CHC constitutes a collective interactional achievement of clinical encounters, the mutual outcome of how patients, caregivers, and providers (and their gatekeepers) engage with one another’. (Shim 2010b, p. 11)

Shim therefore portrays cultural health capital as an interactive process between health care providers, patients, and importantly, family carers. This is important as this extract, taken from the conclusion of the paper, is the first and only time Shim makes reference to caregivers in her paper. I would argue that it would be interesting for Shim to develop this point further throughout the paper, rather than her emphasis on patients. I would also argue that CHC is perhaps more relevant to carers of people with life limiting and chronic illnesses

because, as argued earlier (see chapters 6, 7 and 8), carers often become the patient's advocate when they are unwell or elderly for example.

It is useful to explore the notion of cultural health capital within the context of data from the study. Bourdieu argued that elements contributing to cultural health capital are inherent or embodied within a person, rather than being worked on or performed in some way. In contrast to this assertion, evidence from this study suggests that rather than being inherent, that people have an awareness of the importance of CHC and draw upon this in order to attempt to optimise interactions with health professionals. For example, Bill's narrative is interesting as he clearly indicates his awareness of the importance of cultural capital in the healthcare environment and suggests a relationship between CHC and clinical encounters. Bill cared for his wife at home, before she was admitted to hospital and then to a specialist palliative care ward of the hospital.

"I always made the point, you know...I'm gonna always look smart here and tidy and clean' you know? I want to give a good impression, so my wife gets looked after better. Because you see some people coming in that are scruffs; they wear jeans and all the rest of it you know? So I made sure that when I spoke to the Doctors or nurses etc, I was polite, I didn't raise my voice, I tried to have a clean shirt on every day, things like that, you know and er... I thought it would help anyway, you know.

[pause]

...I think it helped my wife, that she got that just that little bit extra attention, you know.

[And] I said to the guys on the ward "Is it alright if I stay tonight?", you know, they put the curtains round and I'd just sleep on the chair and that, you know. And they used to let me stay, but they wouldn't let other people stay, so I was quite pleased with that. And at the [name of hospital] I used to stay, you know. And I'd nip home in the morning and come back later in the afternoon, things like that...They [the ward staff] were very good like that...

I mean, as I say, you weigh everyone up don't you? They weigh you up like. So if you sit there with your wife nice and quiet, and clean and smart and you're you know, and you don't make a fuss and all the rest of it, you know, they weigh you up who you are". Bill

This quote is interesting as it demonstrates that lay people have an acute awareness of the possible positive impacts of CHC. Bill described how he looked after his appearance and monitored his behaviour in an attempt to seek preferential treatment from staff and to secure better care for his wife, on the basis that health professionals make value judgements about patients and their families. Bill believed that his efforts to display CHC were beneficial, as ward staff agreed to let him stay overnight with his wife, whilst they would not allow others, who he describes as not displaying CHC, to do the same. He also believed that displaying CHC would improve care for his wife, although he does not give any evidence that that was the case. It is also interesting that he judges other patients' family members on these values, indicating the prevalent cultural values in health care settings. Furthermore, the fact that Bill draws our attention to his modified appearance and behaviour and compares this with the behaviour of others indicates that Bill consciously 'performs' CHC. Interestingly, this is in contrast to Bourdieu's theory of the unconscious, habitual nature of cultural capital (Bourdieu [1983] 1986; Shim 2010b), Bill's case is interesting as this phenomenon did not arise in other interviews. That is not to say that this finding is insignificant; rather, it provides a framework for our understanding of other elements of formal and informal interaction and communication.

In addition, the values of CHC may help or hinder professional-patient relationships in terms of how well patients perceive they 'get on' with health professionals (Shim 2010b, p. 10). There is evidence to support this claim in the data from this study. A number of participants commented on their relationship with the health professionals they encountered, particularly where the relationship was especially 'good' or 'bad'. Interestingly, there was evidence of the positive impact of 'getting on' with a professional involved in care. Pat and Jean had particularly positive experiences, whilst others did not.

"He was very fond of this one carer that came, because he'd gotten used to her, and they were two people that got on. You know, you don't always get on with everybody. The other lady, there was nothing wrong with her at all, but he preferred the other one and he wanted her there and she was willing to work those times". Pat

"This is what some of these bloody Consultants and Nurses and Doctors don't understand is that if you walked in to this house erm at half past 8, quarter to 9, any morning you'd have heard gales of laughter and singing er, because erm, er, [names of people] were his regular two [carers] in the morning shift- he used to love singing and still had a good voice and all the rest of it and [name of carer] used to like the pop music, so the radio was

blasting away and er, you know, it was all the old kind of er 60s/70 numbers and, and he'd be, he'd be swinging around under the shower [laughing] And then they'd be singing away as well and it was absolutely- I mean it was wonderful, they were so, they were just brilliant with him and erm, and all of them, er, erm, and they used to chat to him and it, it didn't matter that, you know, so often he had difficulty in er making himself understood, they would just pick on things and, and, you know, respond." Catherine

Conversely, Bill provides an example of the negative effect of not 'getting on with' a health professional. Speaking about one of the consultants who was involved in his wife's care, Bill explained:

"He was very negative, I didn't like him to be honest, and you know when you don't like someone...and my wife didn't like him... and er it's so difficult to... erm... you know, get on an equal footing like with people like that isn't it? You know, it's... as I say you- I probably should have asked more, I don't know but.... I just, I didn't like him... and I sensed he didn't like us".

"Well, because of his sort of attitude and his demeanour, his facial expressions, and you know he's the Doctor, he's the big Consultant, you're just the- you're the person who's coming here like, all that combined if you understand what I mean, it's quite difficult to get a hold of". Bill

This quote is interesting as it gives the reader a sense of Bill's perception of the power dynamics at play in the interaction. Bill gave this response in reply to a question I asked him about if he felt he and his wife had sufficient information about her completing curative treatment and embarking on palliative treatment. Bill's comment that he '*probably should've asked more*' indicates that Bill may blame himself for feeling unprepared about the future of his wife's illness. However, he indicates that the reason for this is due to his interpretation of the power dynamic; 'he's the *big Consultant*, you're just the- you're the person who's coming here' (my emphasis added). It is plausible that Bill's experience here impacted on his decision to utilise CHC in future interactions with health professionals in order to secure more positive or successful interactions. Again, it is not possible to make conclusions here, but it is interesting that Bill makes these observations and chooses to tell it as part of his narrative; it indicates the significance of this experience as part of his experience as a family carer.

It is interesting to consider that cultural health capital may also, as Shim (2010b) suggests, contribute to the perceived success of interactions between health professionals, patients and their family carers.

Although CHC provides a useful framework by which to begin to understand interactions between formal and informal systems of care, and we see evidence of this in the data, it is evident that the picture is complex. Although Shim (2010b) asserts that CHC specifically relates to healthcare interactions rather than access to or quality of services, it is problematic that the majority of carers in this study (who were indeed likely to possess cultural capital and cultural health capital) described such a battle and struggle 'against' the healthcare system. It was not possible to investigate the similarities and differences of those who may possess high or low CHC within the context of this thesis, but may be interesting to explore in secondary analysis and future research.

9.6 Summary

Good communication between formal providers of care, patients and family carers is crucial to achieving optimal care and support. Similarly, excellent communication between professionals involved in a person's care is also vital. As (Thomas 2006, p. 69) asserts 'a bewildering number of people can become involved, sometimes causing a confusing mismatch of services and adding to the trauma of the dying process. Patients and carers appreciate the continuity, coordination and on-going relationship with their primary care team or specialist provider'. The findings presented in this chapter, and throughout this thesis, provide further evidence to support this statement. It could be suggested that the range of professionals involved in a person's care, together with the apparent lack of continuity of care (as reported by participants), is related to poor communication, particularly around giving information on the illness and engaging in conversations around death in cases of community care. By contrast, communication in these areas appeared to improve significantly where a specialist nurse was involved in a multi-disciplinary community care team. The findings presented here are concurrent with the findings regarding patients' perspectives of the involvement of specialist palliative care nurses (Chapple, Ziebland & McPherson 2006). The authors report that an overwhelming majority of participants in their study spoke highly of the specialist nurses and valued their advice on 'practical matters, information given about their disease, emotional support, advice on symptoms, and help with communication' (p. 1011). It is interesting that these positive aspects are so closely related to those reported by carers in this thesis and could be considered as evidence towards to need for specialist and/or palliative care nurses to be assigned to all people with life-limiting illnesses.

The newly launched independent website iwantgreatcare.org allows patients to review the care they receive in different care settings as well as review and provide feedback on individual health professionals. 'Iwantgreatcare' is part of a new initiative that focuses on patient satisfaction with services. The 'friends and family test' is also part of this initiative; the test is based on one simple question, 'would you recommend the services you received to

your friends and family?'. The test has been backed by the government as a key driver to improve healthcare, but has faced criticism from the Quality Care Commission who claim that the test is not fit to measure satisfaction with NHS services, as it is based on the Net Promoter Score, which is used in retail to research brand loyalty (Laurance 2013).

The effectiveness of the friends and family test is yet to be fully debated and assessed. However, from the research undertaken as part of this study I would suggest that improvements in verbal and non-verbal communication between health professionals, patients and their families would significantly contribute to the outcome of any patient satisfaction rating.

Chapter 10

Communication II: Experiencing 'care' in caring: the importance of compassionate care

The previous chapter explored the impact of verbal and non-verbal communication on relationships and interactions between patients, carers and health professionals. This chapter furthers the discussion on communication by considering the role of kindness and compassion in triadic care.

The chapter examines carers' experiences of health and social care and draws on exemplars from the data to demonstrate the importance of compassionate care and the impact of its presence or absence on patients and their families.

Compassionate care emerged as a particularly important factor for family carers in their reflections on the quality of interactions between formal and informal systems of care. Those who experienced compassion and kindness in caring often reiterated positive adjectives when referring to such encounters with health professionals and formal carers. Further analysis of this finding (including listening back to the audio tapes and revisiting field notes) revealed that participants often changed the tone and pace of their voice when reflecting on these experiences.

In 'Communication I', issues around communication focussed on interactions between carers and health professionals. By contrast, the issues around kindness and compassion that are presented in 'Communication II' are more focussed on interactions between patients and health professionals. This is interesting because it highlights diverse nature interactions in triadic care. It also highlights that carers observe interactions between others in the triadic care relationship, as well as being active participants of this relationship.

10.1 Introduction

Crowther (2011) asserts that although words such as 'kindness' and 'compassion' are often used interchangeably, there are important distinctions between the concepts and that this is particularly important in relation to healthcare. She asserts that kindness is a two way process involving an exchange between the 'giver of the act and its recipient' (pp. 172-173). Examples of kindness may include a smile, a greeting or assisting others in need (ibid). By comparison, compassion involves 'putting oneself in another's shoes', and involves a much greater emotional connection (ibid). Crowther asserts that acts of kindness may be carried

out of feelings of duty and responsibility (ibid), such as in a professional capacity or what is seen as polite or socially acceptable.

The NHS Constitution (NHS 2012) states that compassion is a central value of the NHS and is something that can be expected by all staff and patients:

“Compassion: We respond with humanity and kindness to each person’s pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for those we serve and work alongside. We do not wait to be asked, because we care”. (NHS 2012)

This demonstrates the NHS’s recognition of the importance of compassion in health care and indicates that compassion is embedded within the ethos of the NHS.

Importantly, those health professionals and formal carers who family carers considered to be kind and or compassionate appeared to make a significant and lasting impression on family carers. This is important because it is the memories of the caring experience that people are left with after their relative’s death, or to quote Dame Cicely Saunders, founder of the modern hospice movement, ‘How people die remains in the memory of those who live on’ (Department of Health 2008b, p. ii). Dame Saunders’ powerful statement is one that resonates particularly strongly with my interpretation of bereaved family caregivers’ experiences and their interactions with healthcare professionals. It is also a powerful statement for health professionals to be mindful of, as it highlights that health professionals are in a special position to impact positively (or negatively) on this memory. Furthermore, as Dawson-Goodey (2011) notes, small acts of kindness, perhaps simply a smile, can be powerful and meaningful in health and social care.

In this chapter, exemplars from the data are used to demonstrate the impacts of the presence or absence of compassionate care and kindness in health and social care for people with life-limiting illnesses and their family carers. Examples from different care environments are also used with the intention to demonstrate the *impact* of kindness and compassion rather than to generalise care as having or lacking compassion in different care environments.

10.2 Hospice care

The findings of this study suggest that compassionate care was most often experienced in hospices. Carers reported that hospice staff often showed real compassion towards the families of ill relatives and looked after their needs as well as those of the patient.

Interestingly, compassion and kindness towards carers and family members was something that was not spoken about to such an extent in other care environments. It is possible that this may be attributed to the palliative care philosophy of attending to the emotional and spiritual needs of patients *and* their families (World Health Organisation), rather than what may be described as a more medical based model of curative care that focuses primarily on the patient (as described in chapter one).

Pauline spoke about the kindness and compassion showed to her and her husband within a dedicated palliative care environment. Pauline's husband had lung cancer with brain metastases. She had cared for her husband at home with the help of her family, before he was admitted to hospital following a series of seizures. In the last week of his life Pauline's husband was cared for in a dedicated palliative care ward of their local hospital. At the end of her narrative she commented:

"(Upset) Sorry! That was (husband)'s story really. It was very, very sad; [a] terrible experience for us as a family. But that last week for him was lovely. He got the best attention; he got one-to-one nursing; he got so much support, as did our family, from the palliative care team. You know nothing was any trouble for them; there was tea, coffee or toast every five minutes, you know. They were looking after me and the kids as well as looking after him, you know. And then erm after he died they kept on ringing us for a long time; somebody came to his funeral, from the palliative care team, which was lovely". Pauline

She went on to explain:

"The staff were very, very busy because there were twelve very, very ill people around them but they were always there for you, you know if you had any query over anything at all, you know. They were always sort of putting their arm around you and giving you a hug, you know and they were so good". Pauline

The above examples demonstrate the positive and lasting impact of the nurses' compassionate approach to caring on both the patient and patient's family. It is interesting that carers recognise care and compassion whether it be solely focused on the patient, or extended to family carers and other family members. It is also interesting that Pauline describes both practical and emotional support from the nurses as being compassionate. Although she does not say explicitly, this support clearly has a very profound and important effect on Pauline as she talked about it so positively. It is also interesting that she chose to

end her narrative on this point, which again indicates the positive impact of compassionate care on her experience and the memory of her husband's death.

It is important to acknowledge that in hospices (and dedicated palliative care wards of hospitals), death is openly acknowledged and accepted; families are likely to be aware that their relative is nearing death if they are admitted to hospice. It may therefore be considered that there is often a more open relationship between families and staff around death. In addition, hospices often have a much higher nurse/patient ratio than hospitals and other care environments and the physical environment is often much smaller than a hospital ward; the average size of a hospice is approximately 12 beds, whilst the average size of hospital ward is around 30 beds. These are important factors to acknowledge when comparing peoples' experiences of care in different environments. These issues also strengthen the arguments made in this thesis around the importance of preparedness (for death) and continuity of care.

10.3 Hospital care

Whilst Pauline's experience may be described as 'compassionate' care, Catherine's experience demonstrates the importance of kindness in care. Catherine's husband had a diagnosis of both Multiple Sclerosis and colon cancer.

"There was a relationship built with one, one support member of staff. Er, now why that relationship was built with her er was because erm, within, within probably a couple of days of him put on, being put on the palliative care route, I noticed how gentle and careful she was with him erm, and er, how she, you know, she, she really approached [husband] with care, with gentleness and, and did her job very effectively and I actually requested that erm she be the one er who, who you know dealt with him when she was on the ward.

[She] would wash him gently and erm and clean his lips gently and she was, she was the one that stood out for me as the one person who erm, really, really came over as, as, well it just showed that despite being busy that she cared. Erm that's all you wanted really, somebody to demonstrate that caring.

You get the impression sometimes with nurses that erm they think of themselves very much as er technicians these days, not professionals... And the ward sister actually used the word; they are trained as 'technicians' and, and it, it feels like the caring's been driven out of them. Erm, and that's what comes over er a large part of the time, you know, making sure

that the patient's got the medication and whatever else er is required, but the care aspect of it erm you know, just shows in how they relate to the patient erm it's, it's not often there erm, it's, it's too erm too methodical and business like erm, but er, yes this one support member of staff stood out from the rest and er she got [husband] ready for me after he died".

Catherine

Catherine's quote is important for a number of reasons. Firstly, Catherine's assertion that this particular member of staff stood out to her suggests that she had not seen this kind of care demonstrated by other members of staff. Secondly, Catherine notes that she noticed this person's caring approach after he was put on a care pathway. Catherine notes that this lady was a 'support member of staff', so she was unlikely to be a member of a specialist palliative care team or a qualified nurse. It is interesting that Catherine asserts this lady's status as 'a support member of staff' several times and defined her role as largely being based on practical care, such as turning her husband in bed. This is important as Catherine is surprised that a member of staff whose job is primarily to provide practical care undertook her duties with such gentleness and kindness in a way that really stood out and touched her. This is in stark contrast to Catherine's experiences of other nurses at the hospital, who she perhaps had the *expectation* of being kind, gentle and caring but in fact she describes as being cold, impersonal and task orientated. Catherine spoke to the ward sister about her concerns. The ward sister went on to tell Catherine that nurses today are trained as 'technicians' in care. This is important as it indicates that the same 'task' may be carried out, but it is the *manner* in which it is carried out that is important to relatives. This is particularly relevant to the research question posed in this thesis. Finally, Catherine's quote is important as it indicates that kindness and compassion can be communicated through an observation rather than actually being the recipient of a kind or compassionate act.

Research conducted by Maben et al. (2012) indicates that Catherine's experience is not uncommon. The authors observed 'support' members of staff (unqualified staff, students and health care assistants) giving 'very tender and attentive patient care' in their observations of staff on a 'medicine for older people' ward in an NHS hospital (p. 87). The authors associated such behaviour with a 'high demand/low control work environment' and feelings of 'marginalisation' amongst support staff (ibid). The authors suggest that in such environments personal satisfaction could be gained by providing extra care for patients staff viewed as 'good' patients, or 'poppets' (ibid). In comparison, 'difficult' patients often received less care and attention from staff. Indeed, observations and field notes taken during this study supported statements alluding to this. The authors commented that staff caring for a patient who was perceived as 'difficult' was:

‘quite business like...staff didn’t really have any affection for the patient...there was no warmth or real greeting in their dealings with her’.
(Maben et al. 2012, p. 90)

Such ‘favouritism’ is no doubt problematic and evidence suggests that patients themselves are acutely aware of the dangers of being ‘difficult’ and therefore go out of their way to be seen as ‘good’ patients (ibid). This adds a further dimension to researching the interaction between patients, carers and healthcare professionals, as it indicates that patients, as well as carers ‘perform’ their role. This also adds to the argument presented in (section 9.5) regarding cultural health capital.

The research undertaken by Maben et al. (2012) was however restricted to a ward dedicated to care of the elderly. More research in this area is therefore needed in order to establish if these findings can be inferred to other wards in hospital and indeed in community, hospice and nursing home settings. Further research would also allow for a better understanding of the presence or absence of this behaviour in relation to care over the course of the illness trajectory.

10.4 Home care

What carers perceived as a ‘lack of caring’ was also evident in the home care environment. Harry’s wife died at home, in the early hours of the morning, from lung cancer. He called his GP surgery shortly after his wife’s death:

“He [GP] came out, just looked: ‘Has she seen her own doctor within the last two weeks?’, ‘Yes, she came’. ‘When did she come out?’, ‘About three days before she died’. ‘Have you any idea what time she passed away?’. I said ‘Yeah, about half past one’. ‘Right.’ and just signed it. ‘Just phone the undertaker’. And I thought ‘How unsympathetic’”. Harry

Because his wife died during the night, Harry would have been referred to the out of hours GP service for his area. Whilst the use of this example in no way intends to imply that out of hours services are poor, it highlights Dame Saunders’ comment that ‘how people die remains in the memory of those who live on’ (Department of Health 2008b, p. ii). In this case, Harry’s encounter with this particular GP has left a rather negative memory of this interaction at the time of his wife’s death.

In a further example, Rachel cared for her sister at home. She says of the district nurses:

"It was like, you know, [loudly] they'd come in to do a job and they'd do the job and they'd go, and that's it. Do you know what I mean? I don't mean to say like sit and chat, but just be a bit more caring towards her". Rachel

Carers in the study consistently stressed the importance of getting to know the formal carers and health professionals that cared for their relatives. Carers valued a personalised and 'caring' approach to care, whilst dissatisfaction with care was expressed when the care was considered to be 'task orientated', 'tick box' or 'impersonal'. This is an important yet difficult factor in managing the perception of quality of care. Whilst the same task may get carried out, e.g. turning a patient or taking them to the toilet, it is the *manner* in which it is done that is important i.e. whether it be seen as quick and impersonal or done 'with care'. This is problematic, particularly as there is a move to record carers' satisfaction with the standards of care they receive through surveys such as Views of Informal Carers Evaluation of Services survey (VOICES) (Addington-Hall et al. 2011). If compassion in care is a factor in the perceived *quality* of care, as I am proposing, then quality of care may improve if staff know they are being assessed on it.

By contrast, Ann described how her experience changed significantly when a specialised nurse became involved with her mother's home care. Ann's mother was later cared for in a hospice, where Ann also commented on the 'caring' manner she and her mother experienced. Reflecting on her experience, she explained:

"I think the kind of care...the caring and the caring aspect and er, the way they [hospice staff] cared for us as well I think, and the people at the [charity] as well, how [specialist nurse] used to relate to me and I used to relate to her. They were ever so kind. And that's all you need, you know? You just need a bit of...help. And a bit of kindness. And it goes a long way."

"But if people could have a little bit of that kindness, earlier on, then maybe you wouldn't feel as if [pause]-as if it's all coming in on you." Ann

Ann's reflective comments demonstrate the importance of kindness and compassion in health and social care and suggest that she and her family may have had a more positive experience if they had experienced this earlier.

10.5 Nursing and residential home care

Interestingly, there was very little mention on kindness and compassion in nursing and residential homes. Given that this had emerged as an important theme in other care settings, this warranted further investigation. All four cases of nursing and residential care were

revisited in full in order to rule out any possible coding errors, for example. Only one participant, Julia, briefly commented on kindness in regards to the care her mother received. Talking about the quality of care and dignity in the care home Julia said: *‘as long as people [care home staff] were kind to her she would tolerate quite a lot; that was her priority really that people were kind’*. There were however a number of narratives regarding poor care in nursing and residential homes and the indifference of staff to patients, which suggested a lack of kindness and compassion, but this was not spoken about at any length by participants. Conversely, there were other examples of care workers going above and beyond their duties following a person’s death. This is described in more detail in the following section on kindness and compassion post-bereavement. Again, it is important to highlight that there is often a lower staff/resident ratio compared to the ratio and size of a hospice. Staff may be very busy and resources stretched. Again, ‘tasks’ may be performed quickly but it is the manner in which they are carried out that is important to patients and carers.

10.5.1 Discussion

Care and compassion of hospital staff was a key finding of the Francis Report (2010). In the report Francis notes the lack of a ‘caring attitude’ (p. 12) of some staff members:

Although some staff members were singled out for praise by patients, concerns were expressed about the lack of compassion and uncaring attitude exhibited by others towards vulnerable patients and the marked indifference they showed to visitors’ (Francis 2010, p. 15)

The findings of this study concur with the findings of this report and have argued that carers’ perceptions of the attitude of nursing and other hospital staff can have a significant positive or negative impact.

Crowther (2011) presents an interesting argument on this issue; she poses the question of whether care and compassion can be taught or whether is innate and therefore whether such care is interpreted as genuine by family carers. This is a complex issue and, rather than being black and white, is possible that health care professionals and formal carers should be reminded of the importance of carers perceptions of their actions.

Angela Jones, a GP writing into the BMJ ‘Views & Reviews’ section (Jones 2010), offers a health practitioner’s perspective on kindness and compassion in NHS health care. She describes the NHS as a ‘bureaucratic nightmare’, in which standards of care have been compromised and fragmented by ‘super-specialisation’ and the impact of the European

Working Time Directive⁵⁰. She calls for health care professionals to take action; to be mindful of kindness at all times and to carry this through in their day to day interactions with patients and other staff. The evidence presented in this chapter suggests that Jones' comments about being mindful of kindness in their day to day practice are particularly poignant and importantly, may be achievable in the health and social care system.

Indeed, other health practitioners have made observations on the importance of kindness and compassion in health care. The Nursing Times, for example, recently urged all NHS staff to work within a framework of the '6Cs' (Ford 2012). The '6Cs' are central to the 'Compassion in Practice' strategy (2012) and refer to care, compassion, competence, communication, courage and commitment, and are further described below:

Care: *Care is our core business and that of our organisations, and the care we deliver helps the individual person and improves the health of the whole community. Caring defines us and our work. People receiving care expect it to be right for them, consistently, throughout every stage of their life.*

Compassion: *Compassion is how care is given through relationships based on empathy, respect and dignity- it can also be described as intelligent kindness, and is central to how people perceive their care.*

Competence: *Competence means all those in caring roles must have the ability to understand an individual's health and social needs and the expertise, clinical and technical knowledge to deliver effective care and treatments based on research and evidence.*

Communication: *Communication is central to successful caring relationships and to effective team working. Listening is as important as what we say and do and essential for "no decision about me without me". Communication is the key to a good workplace with benefits for those in our care and staff alike.*

Courage: *Courage enables us to do the right thing for the people we care for, to speak up when we have concerns and to have the personal strength and vision to innovate and to embrace new ways of working.*

Commitment: *A commitment to our patients and populations is a cornerstone of what we do. We need to build on our commitment to improve the care and experience of our patients, to take action to make this vision and strategy a reality for all and meet the health, care and support challenges ahead.*(Department of Health & NHS Commissioning Board 2012, p. 13)

⁵⁰ An EU law, implemented in the UK in 1998, which sets standards for maximum working hours within defined periods of time (NHS North-West Deanery 2013).

It is particularly interesting to note the definitions of 'care' and 'compassion' here. In their definition of 'care', the strategy notes the importance of 'consistency' in care. The findings of this study have highlighted this as a particularly problematic issue (see chapter 8). Furthermore, compassion is interestingly described as 'intelligent kindness' (pg13). This definition is not justified further, but could be interpreted as meaning being 'conscious' or 'purposeful' in its intent. If this interpretation is correct, it makes the NHS' position in the argument of whether compassion and kindness are inherent or can be learnt by individuals clear; that compassion is a learnt behaviour.

In regards to compassion, the strategy's definition asserts that compassion is 'central to how people perceive their care' (pg 13). This is a particularly important statement and one which I believe carries a great deal of weight and significance. As argued earlier in the chapter the findings of this study suggest that care provided by health care workers and other health professionals is evaluated as being higher quality or is in some way *worth more* if it is conducted in a kind and compassionate manner. This comes back to the concept of caring for somebody as a 'person' who is 'cared for' rather than the problematic 'task orientated' approach to care that participants describe. Kindness and compassion in health care will prove to be particularly significant as the culture of performance monitoring and evaluation of services in the NHS gathers momentum, such as through the VOICES survey, the 'friends and family test' and 'iwantgreatcare', for example.

It is very encouraging that the importance of compassionate care has been recognised at a senior level within the NHS. The strategy document acknowledges informants' comments the vision of the 6Cs 'will not become reality simply by publishing a document. Frontline staff are the people who can and will make change happen' (pg11). However, at the time of writing, there were no guidelines detailing how such values were envisaged to be implemented. Full implementation plans are expected to be published by 31st March 2013 and are expected to suggest a three year implementation programme (pg12) that are linked with other strategy and policy documents.

The values behind the 6Cs are undoubtedly important, however, a recent paper by Maben et al. (2012) commented that:

'Registered nurses and medical consultants noted the contradictions between the Trust's promise to ensure 'excellence in patient care', their personal and professional aspirations for delivering good patient care and the reality of the workplace' (p. 87).

Here Maben and colleagues asserts a dichotomy between the vision and values of the NHS (in principle) and its staff and the structural and organisational factors within the NHS which the authors suggest act as a barrier to achieving good patient care. This leads us to consider whether the 6Cs can truly be implemented at a time of austerity and further cutbacks within the NHS.

A further argument on kindness and compassion is presented by Ballatt and Campling (2011). The authors argue that NHS staff face a variety of very difficult situations everyday in their work yet are shown little kindness or compassion on an organisational level in acknowledgement of their role (Ballatt & Campling 2011; Heath 2012). The authors argue that frequent restructures and reform detract from the difficulties faced by patients and the professionals caring for them. They argue that ‘a culture of kindness throughout the organisation’ in order to “help frontline staff to help patients” (Heath 2012, pp. 1-2). The implementation of the ‘6Cs’ is timely in regards to the ideas raised in this book. Time will tell if the strategy is successful in its aims and may go some way to achieving the ideas presented by Ballatt and Campling (2011).

10.6 The continuing significance of kindness and compassion post bereavement

For many carers, the significance of kindness and compassion to family carers continued following their relative’s death. Many carers described the personal importance of the presence of a health professional or formal carer at their relative’s funeral. This interesting and unanticipated finding was asserted by the majority of participants in the study, indicating its importance. Interestingly, family carers also commented where health professionals and/or formal carers were absent from their relative’s funeral. This is not to say that a health professional *should* attend a patient’s funeral (indeed, it is a lot to ask of health professionals and formal carers and is likely to be something they would have to do in their own time) but it emphasises the significance of this gesture to family carers. The following quotes from Robert and Barry illustrate this point.

“And they [district nurses] came in and they were very good, and even came to her funeral. That’s how nice they were”. Robert

“They came to the funeral, which was nice. Er, one of the nurses [formal carers] came and [name] the Macmillan nurse came. They came to the funeral, so I thought that was very nice”. Barry

The following quote from Julia offers a further insight; she explains how the attendance of a particular nurse at her mother’s funeral meant a lot to her because it showed a personal connection and real caring for a person, rather than a patient being ‘a number’. This is

important because it demonstrates the significance of the development of personal relationships in triadic care. Julia's mother died in a nursing home.

"I was very happy for any member of staff who felt they were a friend of my mum's to come to her funeral but I didn't want the management to come in any sort of role of just being a representative of management because it was a funeral and it was for friends and family and it wasn't for official (inaudible). They probably took umbrage I don't know, I never heard and some people did come some members of staff did come on that basis".

Julia

It is interesting that family carers described funeral attendance and post bereavement phone calls as acts of kindness and compassion. It suggests the importance of genuine personal relationships, developed over time, rather than an act associated with the duties and responsibilities of a person's professional role. Contact from familiar health professionals post bereavement was similarly described in terms of kindness, outside of what carers considered to be formal bereavement support.

"And then erm after he died they kept on ringing us for a long time; somebody came to his funeral – from the palliative care team which was lovely...And they kept ringing all the time to check on us". Pauline

Mary also commented on her relationship with the nursing home staff following her husband's death:

"When I see them now, they actually come and put their arms round me, you know if I meet them in the town and that, so....we were lucky with the [nursing] home". Mary

Geraldine also spoke of her experience of kindness from nursing home staff following her father's death. She felt that the staff there were kind and supportive to her and her mother.

"Even when my dad passed away, 'Just come in any time. You can even have your dinner with us' and you know. I think once or twice she might have had lunch with them". Geraldine

Finally, reflecting on her mother's death, Jane noted the absence of a social worker from her mother's funeral. She attributed this to a lack of continuity of care.

"My dream would be to see that integrated package and with a social worker who talks to the consultant and who is available and who works with

a very limited number of patients...but who gets to know them well and who sees them through. I would have liked there to be a social worker who'd known Mum that I felt I could invite to the funeral, like I invited the consultant, but there was nobody. So it's a big dream I know, 'cos the NHS doesn't have money but that's what I think we should aim for – that's what I would have liked". Jane

Jane's 'dream' of integrated care fittingly links with issues discussed earlier in the thesis and leads to a discussion of these findings.

10.6.1 Summary

This chapter has considered the role of kindness and compassion in the care of people with life limiting illnesses. The examples here are taken from interviews with bereaved family caregivers. If the narratives and extracts from bereaved family caregivers were to be taken at face value then one would be rather sceptical of the extent to which care and compassion exists in NHS healthcare today. However, this chapter has attempted to put these stories into context by presenting research findings from studies undertaken with healthcare practitioners themselves. Although these are not the 'same' healthcare practitioners there is clearly evidence to suggest that compassionate health care is compromised by structural issues, bureaucracy, understaffing and fragmentation of services. A similar view is shared by Ballatt and Campling (2011) who argues that 'too often structure and culture impede rather than enable good team working' (p. 81). It is therefore difficult to see how the care and compassion strategy and the 6Cs will be successfully implemented to make a real difference for patients and their families under the economic difficulties currently faced by the NHS.

Chapter 11

Discussion and Conclusions

11.1 Discussion of the findings

The research undertaken in this thesis has uncovered a mixed picture of health and social care for people with life limiting illness and their family caregivers. Examples of both good and poor quality care have been demonstrated throughout this thesis. Iles (2011, p. 4) notes that

‘The vast majority of people working with the NHS are good people: not saints, but competent people who have good intentions who are behaving rationally within the situations they face.’

This sentiment was echoed by one of participants, Graeme:

“All the people I’ve met, they’ve all been fantastic, absolutely superb, but it’s just the odd one or two let the system down”. Graeme

The findings presented in this thesis have illuminated the experiences of family caregivers and have highlighted issues at both a structural and personal level in health and social care provision. It may be useful to consider that small changes to healthcare practices may have the potential to make a significant positive impact on the experiences of patients with life limiting illnesses and their family caregivers.

Carers perceptions of the quality of care and support appears to have a significant impact on family carers and the memories that ‘live on’ with them after their relative’s death (Saunders, cited in Department of Health 2008b). This sentiment is echoed in an article by Rabbi Julia Neuberger, on her personal experience of care:

“My personal experience of the past few years has taught me that those last few days colour one's memories permanently. The pain of loss is still immense, but to feel that everything that could have been done was done, that those who cared did so with knowledge, professionalism, devotion, and even love, and that the person died without pain, comfortably, with those they loved around them, is to feel immense gratitude and a curious humility. I now know that superb care is possible within our often stretched NHS. What I do not understand is why it is not available for everybody alike, at home or in a hospice, nursing home, or hospital”. (Neuberger 2003, p. 34)

This thesis has provided examples of both good and poor care in order to provide evidence of the positive or negative impact on family caregivers.

Maben et al. (2012) argue that there is a dearth of mixed methods studies that consider both patient and health practitioner work in acute and community settings. The authors argue that instances of what patients may perceive as poor care come about as a result of what nurses refer to as a 'moral dilemma', particularly in care of older people in acute setting. In their study, Maben and colleagues report that staff reported that understaffing and/or patients with high dependency needs meant that other patients were overlooked or given a bedpan or commode rather than being assisted to the toilet by staff, for example (Maben et al. 2012, p. 86). Staff also noted that they wanted to provide psychological care as well as physical care and to get to know patients, but were unable to do this because of understaffing (ibid). Consultants on the ward also voiced concerns regarding poor patient care due to inadequate staffing. Patients who were interviewed also gave examples where they refrained from asking staff for assistance as perceived the staff as being 'so busy' (Maben et al. 2012, pp. 89-90).

Evidence provided throughout this thesis indicates that family carers are often dissatisfied with access to and quality of support services. In addition to the impact of the experiential nature of such dissatisfaction, dissatisfaction with quality of support services is also associated with psychological distress (Kinsella et al. 2000) and post-bereavement deterioration in health (McNamara & Rosenwax 2010). Furthermore, the presence or absence of 'care' in caring, as interpreted by family caregivers, was crucial to carers feeling supported, and appears to be a significant factor in how family carers cope with their experience after their relative's death.

Many existing studies focus on particular time points in the illness trajectory, particular places of care or particular groups of health professionals. This research is valuable, as it offers the opportunity to improve specific aspects of care. Additional research designs, such as longitudinal and retrospective studies are also important, as they offer valuable insights into carers' experiences over time and highlight common issues that appear throughout the illness trajectory. Exploring a person's experience over time may lead to less fragmentation, enabling commonalities to be seen and highlighting issues around co-ordination of care. The research presented in this thesis contributes to this area of research and provides an insight into the experiences of family caregivers and their interactions with health professionals when caring for their relative. A body of knowledge that incorporates findings from a range of research designs is most likely to provide a balanced and accurate picture of family carers' experiences of caring for a relative with a life-limiting illness. Research incorporating the

perspectives of health and social care professionals and the views of patients is also important to present a balanced view.

A recent systematic review (Herber & Johnston 2012, p. 8) identified that formal caregivers frequently cited that on-the-job training was inadequate training for end of life care and asserted the need for more formal training in this area (Denham et al. 2006; Miskella & Avis 1998). The review noted that in contrast, a study by Clark, Ferguson and Nelson (2000) found that the majority (over 70%) of Macmillan nurses reported that their initial training enabled them to provide comprehensive end of life and palliative care to patients and their families.

Herber and Johnston (2012) highlight that the Department of Health (2000) states that all staff involved with end of life care should receive specialised training. However, their review highlights that this is not happening in practice (pg9). The findings presented in this thesis further highlight the need for specialist training in palliative and end of life care.

“A death dominated by fear, crises, inappropriate admissions, overmedicalisation, and poor communication can be a tragedy and a failure of our medical system: enabling a peaceful death at home can be a great accomplishment for all concerned”. (Thomas 2006, p. 73)

The findings presented in this thesis suggest that failures in the medical system (ibid) occur all too often, irrespective of disease group. Rose and Glass (2006) assert that there is a lack of research into the roles of district (or community) nurses who provide care and support to patients and their family carers at home at the end of life. Although research in this area is limited (Rose & Glass 2006), a number of studies conducted with district nurses demonstrate the value and importance that district nurses and formal caregivers place on caring for patients and supporting their families at the end of life. The findings reported in this thesis however, suggest that, in many cases, carers perceive that this is not being achieved. This is very important, as it leads us to question the barriers that prevent these values being turned into actions that are positively interpreted by family caregivers. Rose and Glass (2006, p. 590) suggest that the increasing demands on community nurses has a significant impact on the quality of care provided. This results in tensions arising between community nurses' desire to deliver humanistic care against the structures in which they work (pg 590). This is an important point and should be investigated further in future research. The findings from this thesis suggest that these values often fail to be interpreted by family caregivers, who frequently reported care as being disjointed and task orientated.

Previous studies have identified a dearth of research into the role of home care workers/formal caregivers in end of life/palliative care at home (Devlin & McIlfatrick 2010). Devlin and McIlfatrick contribute to what is known in this area in their study which was conducted with home care workers and community nurses. Whilst this addresses the problem from the stance of formal caregivers themselves, a dearth of literature still remains from the perspective of family caregivers. What are the similarities/differences between the accounts of the work of formal carers and the experience of family caregivers? This study contributes here.

It may be useful to draw upon research investigating training in supportive and palliative care. In a mixed-methods study on the roles of formal caregivers, Devlin and McIlfatrick (2010) identified that two-thirds (64%) had not received training in palliative and end of life care (pg 199). The authors identified that formal carers' training needs included 'communication skills, end of life care, dealing with death, dying and loss, information on specific conditions and subsequent care required, and palliative care awareness' (ibid). District nurses have also reported a lack of adequate training in palliative and end of life care (Herber & Johnston 2012). It is therefore unsurprising that the quality of care and support was reported as being insufficient by family carers in this study. This is likely to impact on the interactions between carers, patients and health and social care professionals, in the provision of triadic care.

11.1.1 Working towards co-ordinated care: implications of the study findings

As identified earlier, the findings of this thesis are concurrent with the findings of the 'Caring for our future' white paper. The white paper highlights the need for a unified understanding of what is often called 'integrated care'. However, it asserts that language around 'integration' often leads health professionals to think about joining up systems and services (Acton 2013). In contrast, the term 'co-ordinated care' recognises the goals of integration from a service user perspective (ibid). The findings of this study have highlighted the importance of co-ordinated care to family caregivers. The findings revealed that co-ordinated care was often not achieved. Supporting the findings of Lowson et al. (2012), carers often found themselves in the difficult position of trying to find out what services were available and how to gain access to these services. Those who didn't were often left without support. Carers who had a specialist nurse involved in their care were least likely to raise issues of co-ordination of care once this person was involved in care.

Carers frequently highlighted the problem of not knowing who to turn to for different aspects of advice and support. This problem may be related to the issue of role ambiguity, which was outlined in the roles and relationships chapter. However, it is clear that carers are unclear about who to contact for advice and support and highlights the need for clear information

about the roles of professionals in multi-disciplinary teams. This issue could be addressed through a simple intervention, such as an information leaflet, listing the roles of different health professionals and who to approach for different aspects of support. It is possible that this may happen already, but people may get overwhelmed with information. This issue is important and further research with family carers may help to readdress this important issue. Rather than being given numerous contact numbers and taking personal responsibility for co-ordinating care, it may be useful for carers to have a single contact who would arrange for an appropriate person to assist with a carer's specific support needs.

The carer support needs assessment tool (CSNAT) is intended to be used by district nurses to help identify the support needs of family caregivers (Ewing et al. 2012; Ewing & Grande 2012). A challenge here however is that it depends on when the assessment is carried out, as support needs are likely to change over time. The tool is evidence based and was developed in consultation with current family carers, bereaved family carers and district nurses. Overall, the findings presented in this thesis are consistent with the findings of the CSNAT study, which identified carers' needs for more information on their relative's illness as a key priority (Ewing et al. 2012; Ewing & Grande 2012). Consistency between findings also validates the data gathered and analysis undertaken in this thesis.

11.2 Interactions between themes: the 'essence of experience'

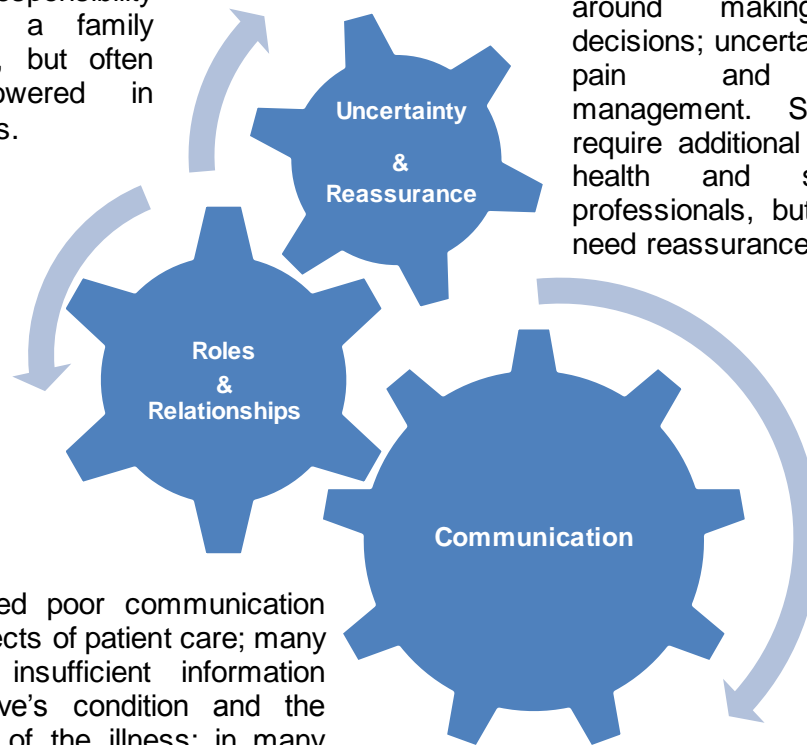
The themes identified in this thesis are inextricably linked, and together form a common story of the experiences of family caregivers who care for a relative with a life-limiting illness. Together, these elements form what is described in phenomenology as the 'essential structure' of a phenomenon (Holloway & Todres 2005, p. 111). This structure refers to

'expressions of patterns or 'wholes' that coherently make sense of the examples on which they are based. These expressions of patterns are able to conceptually describe and qualitatively organize the 'whatness' of a phenomenon and how its elements inter-relate and function together' (ibid).

This study has outlined examples of good care and best practices, but has also highlighted examples of poor care and support, which have a negative effect on family carers. Each component offers opportunities for improvements to be made.

Family carers become 'experts' in the emotional and physical wellbeing of the person that they are caring for. They take on a position of responsibility when caring for a family member at home, but often become disempowered in clinical environments.

Carers feel that there is a great deal of uncertainty in many aspects of their experiences. This includes: how the illness is likely to progress and how to prepare for this; uncertainty around making 'medical' decisions; uncertainty regarding pain and symptom management. Some carers require additional support from health and social care professionals, but mainly they need reassurance.



Carers experienced poor communication across many aspects of patient care; many carers received insufficient information about their relative's condition and the likely progression of the illness; in many cases there was also a dearth of information regarding their relative's current stage of illness; many carers found 'patient confidentiality' was a barrier to gaining the information they felt that they needed; there were also difficulties engaging in end of life discussions. Compassionate care is central to the perception of 'good' care.

Figure 16: The 'essence of experience'

11.3 Cancer and non-cancer patients

The research question for this thesis originally intended to examine differences between the experiences of carers of people with cancer, neurological disease and respiratory disease. As explained in the introduction to this thesis, more commonalities arose from findings than differences between groups, which led to the research question being amended to reflect the issues emerging from the data.

A small scale qualitative research study with district nurses indicated that the level and quality of end of life care given to patients in the community varies depending on whether

they have a cancer or non-cancer diagnosis (Law 1997). Thomas (2006) also argues that palliative care services in the UK favour patients with cancer, with those with other life limiting conditions receiving reduced access to services and specialist advice. She argues that the management of care available to cancer patients should also be used as a model of care for non-cancer patients (pg 71).

The findings of the recent VOICES survey, involving 22,000 bereaved caregivers, found that carers of people with cancer, who were under 65 years old, were most likely to rate care in the last three months of life as 'excellent' or 'outstanding' (Department of Health 2012b). Further analysis of these data may be useful in determining differences between service provision for people with different conditions (from the perspective of bereaved informal carers).

The findings of this thesis indicate that the provision and quality of formal care is inconsistent for patients and families across all disease groups (including cancer) and across different places of care. This is an important finding; if, for example, care for a particular demographic of patients and carers was found to be good it would be possible to develop principles of best practice. This study found deficiencies in basic principles of care, across all disease groups and this should be urgently addressed. Furthermore, the evidence presented in this thesis suggests that the Gold Standards Framework (National Gold Standards Framework Centre 2008) is not being consistently and effectively utilised in the last year of life, particularly regarding 'carers feeling supported, involved, empowered, and satisfied with care' (Thomas 2006).

11.4 Discussion of findings in relation to research and policy

This section addresses how the findings of this thesis fit in with the wider picture of policy, practice and research in this area.

The findings presented in this thesis may be used to enhance interactions between patients, carers and health and social care professionals (Guo, Phillips & Reed 2010) in different places of care, through the illness trajectory.

It is also useful to revisit Hudson's comments regarding future directions in supportive caregivers in palliative care when considering the implications of the findings presented in this thesis.

'Unless there are substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils, palliative care will fail to deliver upon its

core function of adequately supporting the patient along with the family’.
(Hudson & Payne 2011, p. 867)

With this reference in mind, the key findings are discussed with reference to research, policy and practice.

11.4.1 Research

Crucially, literature in this area of research is now focussing its attention on interventions to support family caregivers (Grande et al. 2009), with interventions covering dimensions of practical, physical and emotional support needs. Whilst it is apparent that carers *do* require support in these areas (and tools such as the CSNAT are useful in identifying support needs and then addressing them) it seems that attempting to address these needs *after* they have been identified as problematic only attends to part of the issue. In addition to designing interventions to support family carers, more attention should be paid to improving health and social care professionals’ skills in communication and basic care and in identifying barriers to the implementation of these skills. It is imperative that aspects of practical, physical and emotional support are addressed early on, in order to minimise caregiver burden, stress, worry and burnout and positively impact on the caring the caring experience of family members in a supportive and proactive way.

Whilst the CSNAT aims to identify key areas in which family caregivers require additional information or support, the Views of Informal Carers Evaluation Survey (VOICES) aims to evaluate services in the last stages of life (Addington-Hall et al. 2011). The VOICES survey was specifically designed to be completed by bereaved caregivers. It was recently adopted by the Department of Health (2012b). Further analysis of the data is likely to reveal key areas of focus for future research.

11.4.2 Policy

It is useful to discuss the findings presented in this thesis in relation to the recent white paper ‘Caring for our future: reforming care and support’ (Department of Health 2012a).

The white paper outlined the following issues in the provision of health and social care:

During our Caring for our future engagement in autumn 2011, we heard from thousands of people who use or work in care and support. Many told us how high-quality care and support had transformed the way they live their lives. However, others said the current system was letting down older and disabled people. We heard that:

- *too often the system only reacts to a crisis;*
- *society is not making the most of the skills and talents that communities have to offer;*
- *people do not have access to good information and advice;*
- *access to care varies across the country and is confusing;*
- *carers have no clear entitlement to support;*
- *not all care is good. The quality of care is variable and inconsistent;*
- *people often feel 'bounced around' and have to fight the system to have the joined-up health, care and support they need.*

(Department of Health 2012a, p. 7)

The findings reported in the white paper largely support those presented in this thesis⁵¹. This white paper outlines the government's plan to reform health and social care provision into a new 'person centred' system (Department of Health 2012a, p. 9). The findings reported in this thesis relating to the current picture of care (as depicted through models and supported with experiential data) may offer policy makers the opportunity to gain further in-depth insights into the experiences of family carers, across the illness trajectory and in different places of care. The findings presented in this thesis provide further evidence of what 'person centred' health and social care may include, for example, the study highlights the issue of uncertainty and the need for reassurance for carers providing home-based care. A 'person-centred' approach may provide ongoing proactive support to patients and family carers, rather than reactive care in times of crisis.

The findings presented in this study also share similarities with the findings of the Francis Report (Francis 2010). The Francis Report repeatedly highlighted issues regarding understaffing, failures in basic nursing tasks and the lack of a 'caring' attitude of some staff towards patients and their relatives. The report highlighted cases where there was a lack of 'basic nursing tasks', as well as more 'systemic failures' (ibid). Although there were examples of good care in hospitals reported in the present study, the findings suggest that failures of this kind are not restricted to Mid Staffordshire Hospital Trust. The recommendations made in the Francis report should be considered by other hospitals and Trusts in order to raise standards of care and improve interactions between patients, their carers and relatives, and hospital staff.

⁵¹ This also provides further validation of the findings presented in this thesis.

11.4.3 Catalytic utility: implications for healthcare practice

The findings of this study offer numerous opportunities for application to clinical practice. Firstly, this study gives family carers a 'voice' and in doing so, raises awareness of the experiences of family caregivers to both the public and to health and social care professionals.

The findings highlight that small changes may have the capacity to make a significant difference to patients and their families. This includes showing kindness and compassion in care (particularly in hospitals and at home). The data suggests that it is the *manner* in which caregiving tasks are conducted that is important to patients and carers. This is important, as this finding is easily transferable to clinical practice, even in environments where there may be issues of understaffing.

Clear communication is also vital and has the potential to make a hugely positive impact on carers' experiences through reducing unnecessary uncertainty and increasing feelings of reassurance. It is useful to discuss this issue in relation to models of disease progression depicted in Figures 1 and 2.

Uncertainty around illness progression was a key feature of the experiences of study participants. For example, a carer of a person with COPD explained how she had associated her husband going into hospital with alleviating his symptoms and was therefore not prepared for his death on his last admission to hospital. Furthermore, many carers explained how they felt that they lacked information about the 'stage' of their relative's illness and that healthcare professionals were often reluctant to address this directly. It may be useful for healthcare professionals to share diagrams such as figures 1 and 2 with family carers and to talk through the likely illness trajectory at an appropriate time.

Trust was a central concept in family caregivers' experiences. In many cases trust may be achieved by building an on-going professional relationship with health and social care professionals. Continuity of care and 'getting to know' the people involved in their relative's care was central to the development of trust. This should be taken into account in future revisions of service provision, particularly in community care.

The findings of this study suggest that, in addition to these small changes, structural and procedural changes should be made in order to reassure family caregivers and support them in their role. Improved communication and the provision of timely information are essential here. Proactive care and support (health and social care professionals making supplementary informal contact with family carers) may hold the key to reducing unnecessary uncertainty and increasing carers' confidence and feelings of reassurance and support.

Finally , having a named contact or specialist nurse may also be key to reducing uncertainty and ease the weight of responsibility of care from carers, allowing them to spend more quality time with their relative as their spouse, daughter or son, as well as being their relative's 'carer'.

11.5 Strengths of the study

The study has methodological strengths as well as strengths relating to the key findings. Both are discussed here.

11.5.1 Methodological strengths

Retrospective research allows for the privilege of hindsight and reflection on circumstances that are very important for health services research. This is particularly so in studies involving family carers, as many carers asserted that they 'take each day as it comes'. Research with active carers and longitudinal studies also have benefits, as they may allow an in-depth insight into a specific issue, a specific point in time or give an insight into change over time. Retrospective research provides a further dimension to understanding carers' perspectives of their experience.

Another strength of this study is that it addresses the whole of the illness trajectory. Many studies focus on a specific stage of illness. Indeed, this study originally aimed to focus on end of life, but was amended to include the whole of the illness trajectory as carers raised many important issues prior to the end of life stage. To dismiss this would not be being true to the data or the participants.

A further strength of this study is that the narrative focus of interviews allowed for an insight into the most important issues for family carers.

11.5.2 Key findings

11.5.2.1 Continuity of care

Issues around continuity of care were key findings of this study, which was closely linked to feelings of uncertainty for family carers. Feelings of uncertainty regarding continuity of care was particularly prevalent in home and hospital environments, where building relationships with health and social care staff held particular importance for both patients and carers. Carers reported that their relatives emphasised the importance of 'getting to know' and 'feeling comfortable' with those caring for their relative and building trust. Many participants emphasised the importance of feeling that their relative was in 'safe hands' with a person who is familiar with the patient, and was somebody that both the carer and patient had come to know and trust over time. This issue was prevalent across all disease groups in the study.

The findings highlight the importance that family carers attribute to continuity of care, particularly in regards to care at home. The findings indicate that continuity of care is central to positive interactions between formal and informal systems of care. Although potentially challenging, providing continuity in care, particularly in the community, should be considered best practice by health and social care providers in the UK.

11.5.2.2 Models of care

The findings of this study emphasise the complex, dynamic and changing nature of caring relationships over time and in different places of care. Existing models of dyadic and triadic care fail to capture such complexities. Figures 11-14 were developed from the data and attempt to portray a more detailed representation of the interactions between informal and formal care in different care environments. The models are set within the context of the findings and discussion presented in this thesis.

Home

Figure 12 illustrates the emergent picture of home based care for people with a life-limiting illness and their family carers. In this model, a family member acts as their relative's main carer, with the carer and patient receiving some degree of support from both formal and informal systems of care.

Hospital

Many people with life-limiting or terminal illnesses spend periods of time in hospital; this may be a temporary admittance before being discharged home or to a hospice or a nursing home, whilst others may die in hospital. For many, the move from home to hospital involves a shift in the primary responsibility of care from informal to formal systems of care, where family members traditionally play a supportive rather than active role in care. The narratives from participants in this study suggest that the shift in the dynamics of care between home and hospital based care was often a difficult and complex negotiation.

Figure 13 depicts that the patient remains supported by the main caregiver and (often) other friends and family, that the main responsibility for care is provided by healthcare professionals (formal care).

Hospice

A number of participants in this study attended hospice day care, had a period of respite care, or a short stay in a hospice to assess their medication. For others, their relative received inpatient hospice care up until their death.

In palliative care in a hospice (or a designated palliative care ward in a hospital), formal systems of care provide the main clinical care, and in keeping with the ethos of hospice care, also provide a supportive role in the patient and families' emotional and spiritual wellbeing.

In contrast to the dynamics between informal and formal carers in the home and hospital environments, hospices appear to strike an appropriate balance; they work closely with the patient and the family and have a more personalised approach to care. It appears that hospices recognise that the important value of family carers, are attentive to their needs and involve them in the patient's care. Achieving this balance, hospices provide a special environment for families, as they take away the 'hard work of caring' (Crowther 2011) and allow people to be themselves, allow special or quality time for families to be together without all the extra worries that come with caring.

It is important to recognise however that the findings presented here are based on the experiences of the study participants. It is not the intention to suggest that hospice care is universally perfect or without fault. However, the positive experiences presented here do support those of other studies in this area (Addington-Hall & O'Callaghan 2009).

11.6 Limitations of the study

The findings presented in this thesis are limited to those who took part in the study and, like all qualitative research, are not intended to be representative of all carers who have cared for a person with a life limiting illness. This sample was limited to carers of people with neurological disease, respiratory disease or cancer. The interviews which informed this study took place between July 2009 and July 2011, with carers being bereaved up to five years prior to the interview. Furthermore, the majority of the research was carried out in the North West of England. The findings of the research therefore may reflect the experiences of people in this geographical area between these particular years. The research therefore does not intend to suggest that the findings presented in this thesis are representative of the current picture of health and social care in the UK, but highlights important issues that were common across participants' experiences and should be taken into consideration to inform future government policy, practice and research in this area. It is also acknowledged that those who had negative caring experiences may have been more motivated to participate in this study (Whitehead et al. 2012, p. 376).

The research reported in this study took place with carers up to five years post-bereavement. There may therefore be the potential for emotional and recall bias (Guo, Phillips & Reed 2010, p. 342).

A further limitation of the study is that the views and experiences of health care professionals, formal carers and patients have not been expressed. It is acknowledged that these groups may have had different interpretations of events than those that carers in this study expressed. Nevertheless, strong themes emerged from the data reported in this thesis, which indicates some commonalities in participants' experiences. Raising commonalities that were seen as problematic or unsatisfactory by carers is useful as it raises important issues and gives carers a 'voice'. It also creates the possibility for these issues to begin to be addressed.

There were too few cases of nursing home care to comment in any detail. Further research is required in this area in order to better understand the interactions between formal and informal systems of care and people with life limiting illnesses.

The lack of contact with participants to review the emergent findings may be considered a possible limitation of the study. The merits of 'member checking' or 'participant validation' are subject to debate in the literature in qualitative research methods. Consulting participants offers a further means of validating the findings; to verify that the interpretations and findings drawn are correctly represented (Marvasti 2004). Conversely, Silverman (2006) asserts that participant validation is not always desirable. Participant validation of emergent findings through focus groups may occur in qualitative research, but is not general practice. Data analysis is a highly interpretive process. For this reason I decided not to conduct focus groups for participant validation. As asserted in the methodology chapter, phenomenology recognises that knowledge is the co-production of the stories told by participants at a particular time, place and culture, and the interpretation of the researcher within a specific time, place and culture.

As with all qualitative research, the findings presented here are not intended to be representative of the population; phenomenology recognises that findings reflect the experiences of the participants and interpretations of the researcher(s) within time, location and other cultural contexts. However, it should be recognised that the high proportion of participants whose relative died at home (compared to the national average) may be considered to hold some sample bias. Furthermore, many participants who took part in the study were both articulate with health and social care professionals, and were articulate in telling their story. This may not be representative of the wider population of family caregivers.

11.7 Findings in relation to models and theories of care

Current models of triadic care fail to adequately demonstrate the complex interactions between patients, family caregivers, other systems of informal support, and health and social care professionals. The models proposed in this thesis draw upon research evidence gained through detailed accounts from a large number of caregivers to develop more dynamic models of care, which reflect the current experiences of family carers.

11.8 Proposed model of support arising from the data

Figures 11-14 represent the interactions between informal and formal systems of care, in different care settings, based on the study findings. By contrast, figure 17 proposes a model of support for carers and patients.

This thesis has highlighted the need for basic improvements in care for all carers and patients and supports findings highlighted elsewhere (Francis 2010; Guo, Phillips & Reed 2010). Improvements in basic care are likely to provide a solid foundation for additional, more specific care to be included. This may include, for example, disease specific or trajectory specific support. Tools such as the CSNAT (Ewing et al. 2012; Ewing & Grande 2012) are useful in identifying additional needs and changes in support needs as a person's illness progresses. If used together, these components may provide acceptable and proactive support carers of people with a life-limiting illness (see Figure 17). Additional support needs should be provided within a culture of 'care' in caring; where family carers feel reassured in their role where they are the primary caregiver at home, and feel reassured that their relative is in 'safe hands' in all care environments.

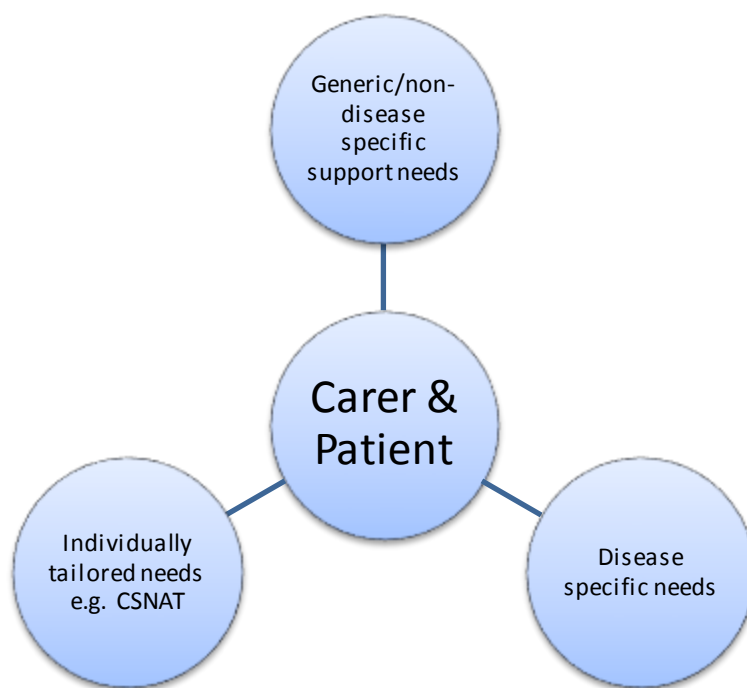


Figure 17: Proposed model of support for carers and patients

11.9 Future research

Further research is required in the area of residential and nursing care in order to better understand the interactions between formal and informal systems of care and people with life limiting illnesses in this environment. It is a particularly interesting area of research, as nursing home environments have elements of home care and hospital care. i.e. a nursing home usually becomes a person's home, or permanent place of residency (unlike a hospital which provides temporary care). A person's main carers are likely to be care home staff with whom they interact with all day every day. Family members take a secondary or supportive role in providing everyday care and support for their relative. Nursing home staff are formal carers may live with a person for a long period of time and care for them until their death. There is likely to be increased continuity of care because of the static environment of nursing homes. These reasons may suggest care more akin to that of family care, yet a mixed picture has emerged from the data from this study and also from the wider literature. Further research is therefore needed in order to better understand triadic relationships between nursing home staff, family carers and their relatives. Such research would also allow for a model of triadic care to be developed for nursing home settings.

A key finding of this study was the importance of proactive, opposed to reactive, care and support to family caregivers. Future research should address this issue directly, through the development, implementation and evaluation of supportive interventions for family carers. A

simple example, based on the findings reported in section 8.4.2 would be for existing services to make phone calls to families whom they support.

This study also highlighted the issues of uncertainty, reassurance and role ambiguity. A key feature of this issue included uncertainty around one's role as a family caregiver. Websites such as 'Healthtalkonline' provide a useful resource for carers, should they wish, to hear others' experiences of caring for a family member with a life-limiting illness. To date, no studies have evaluated the usefulness of this resource to family caregivers.

The findings presented in this study are also based solely on caregivers' perspectives and experiences. It may be valuable for future research to explore the roles of community health and social care professionals from their own perspectives and to explore how this fits with the models presented in this thesis. Providing health and social care professionals with a 'voice' through research such as this may also provide a valuable source of information for service improvement.

11.10 Conclusions

The findings reported in this thesis contribute to knowledge in several priority research areas, including: the experiences of family caregivers; site of care; family dynamics; role of the family caregiver; communication- health professionals/family; and financial impact (see Table 6 for a full list of priority areas).

Much of the existing research literature is time or illness specific. This study provides an insight into the experiences of carers across the illness trajectory. This research adds a unique contribution to knowledge by addressing interactions between carers, patients and formal systems of care from the perspective of family carers, across the illness trajectory.

The study is unique in that it identifies commonalities between the experiences of carers of people with different health conditions and identifies that there are strong commonalities between the experiences of cancer carers and those with other conditions.

The findings presented in this thesis identified that, overall, carers felt that they and the person they were caring for were fairly well supported at the end of life. This was particularly the case where a specialist nurse had been involved in a person's care or the cared for person was admitted to a hospice at the end of life. Conversely, the period between diagnosis and end of life was often very difficult for carers and patients; many carers experienced a lack of practical or emotional support from formal systems of care, a lack of information and a lack of joined-up services. These factors often contributed to carers struggling to cope with changing support needs as the person's illness progressed.

The findings suggest that that reducing uncertainty and increasing reassurance are important factors in improving the caregiving experience, in both pre-end of life and end of life care, and particularly in the home environment. This may be achieved through proactive support/contact from health and social care professionals, and should be considered as an area for future research.

The findings presented in this thesis suggest that although assessing carers' needs are important aspects of providing appropriate care and support, that small changes and a focus on core principles of communication and compassionate care may be equally important in improving carers' experiences.

The models of care proposed in this thesis relate to carers' existing experiences of care and support in hospital, home and hospice settings. These models contribute to new knowledge by developing the existing models of triadic care.

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Appendices

Appendix 1: Notice of ethical approval

From: Fletcher, Sarah on behalf of Ethics

Sent: 29 June 2009 10:58

To: Lloyd-Williams, Mari

Subject: RE: Re application to be considered please at next ethics committee meeting - RETH000268

Dear Professor Lloyd-Williams

I am pleased to inform you that the Sub-Committee has approved your application for ethical approval. Details and conditions of the approval can be found below.

In order that this approval is valid, please ensure that you send a signed copy of the final version, with all supporting documentation, to the Research Governance Officer, Contract Services, Legal Services, Foresight Building, Liverpool, L69 3GL within 5 days of receipt of this email.

Ref:	RETH000268
Sub-Committee:	Non-Invasive Procedures
PI:	Prof Mari Lloyd-Williams
	Dying from end stage respiratory disease, neurological disease and cancer in the 21st Century: What is the current experience for patients and carers and what makes a difference for carers?
Title:	Dr Mark O'Brien
First Reviewer:	n/a
Second Reviewer:	17/6/09
Date of initial review:	29/06/09
Date of Approval:	9

The application was APPROVED subject to the following conditions:

Conditions

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Sub-Committee should be notified. If it is proposed to make an amendment to the research, you should notify the Sub-Committee by following the Notice of Amendment procedure outlined at <http://www.liv.ac.uk/researchethics/amendment%20procedure%209-07.doc>.

If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the RGO at ethics@liverpool.ac.uk in order to notify them of a change in PI / Supervisor.

Best Wishes

Sarah

Appendix 2: Participant Information Sheet



Participant Information Sheet

Title of the Study: Dying from end stage respiratory disease, neurological disease and cancer in the 21st Century: What is the current experience for patients and carers and what makes a difference for carers?

Invitation

You are being invited to take part in a research study. Before you decide to participate, it is important that you understand why the research is being undertaken and what it will involve for you. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. You may also wish to discuss this with your family, friends and/or your General Practitioner. We would like to stress that you do not have to accept this invitation and should only take part if you wish to do so.

Thank you for reading this information.

1. What is the purpose of this study?

At the moment, we know very little about what happens to people with end stage illnesses and their carers. The purpose of this study is to find out more about this by talking to carers about what happened to them during this time. If we can gather information about what people feel they need, it will help to decide what services people may benefit from and how best to provide these in the future.

Laurie Dunn is a researcher working with the Principle Investigator Professor Mari Lloyd-Williams at the University of Liverpool. Laurie will be working on the project for two and a half years as part of a PhD. This study is being funded by the University of Liverpool and has been reviewed by the University's Research Ethics Committee.

2. Why have I been chosen to take part?

You responded to our appeal for people who had cared for someone, either a family member or a close friend, with an end stage illness (respiratory disease, neurological disease or cancer). We would like to hear about your experiences to help us better understand yours and the needs of others in a similar situation.

3. Do I have to take part?

It is up to you whether or not you take part. This information sheet is yours to keep. If you decide to take part, the researcher will ask you to sign a consent form. Participation is

entirely voluntary and you can withdraw from this study at any time. You do not have to give a reason and you will not be affected in any way should you wish to withdraw. If you do decide to withdraw, the project researcher will ask for permission to use the information collected from you to this point, but you do not have to agree to this.

4. What will happen if I do take part?

If you decide to take part, please contact Laurie Dunn. Laurie will discuss the study with you in more detail over the telephone and will make an appointment to come and see you at a time and place convenient for you, so you can tell them your “story”. Laurie will talk to you again about the study when she visits and provide you with an opportunity to ask questions. You will be asked to sign a consent form before the interview begins and will be given a copy of the information sheet and consent form to keep for your records.

With your permission, Laurie will record the interview instead of taking notes. This will mean they can concentrate fully on what you are saying at all times. The meeting will last about an hour, but this depends upon you and what you have to say. If your interview seems to be taking a long time, you can make an appointment with the researcher to continue the interview at another time.

If you do not meet the researcher in your own home, any travel costs or those associated with taking time from work etc., will be refunded to you, upon provision of receipts.

5. What are the benefits of taking part?

There are no direct benefits to you in taking part in this study. If you decide to take part, you will help us to find out more about what happens to carers and people with end stage illnesses, which may help to inform provision of future services. Nevertheless, some research has suggested that talking about past experiences can be helpful to people.

6. Are there any disadvantages to taking part?

It is possible that telling your story may be upsetting to you. For example, you may be recalling a traumatic event. If you become upset during the interview, Laurie can stop the recording and discontinue the interview. You may feel able to continue after a short break. If you prefer, the interview can be arranged for another time or you may decide not to continue at all. In the event that anything untoward happens to you as a direct result of your participation, this study is covered by the University of Liverpool’s indemnity scheme.

7. What if I am unhappy or there is a problem?

If you are unhappy at all please contact the Principal Investigator, Prof Mari Lloyd-Williams on 0151 794 5605, or Laurie Dunn on 0151 794 8043 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance officer on 0151 794 8290. When contacting the Research Governance Officer please tell them the name of the Principal Investigator and the researcher, the name of the study (see the top of this page) and the nature of your complaint.

8. Will the information I give be kept confidential?

The stories that you tell will be kept confidential. Laurie will make sure that the tape and transcript from your interview are anonymous and kept safe at the University in a lockable cabinet. The only people who will have access to these are Prof Lloyd-Williams and Laurie Dunn. If any of the contents of your interview are used for publications in journals, presentation at conferences or similar, please be assured that these will be anonymous and you will not be identified at any stage. Any personal details you give to enable us to send information and to contact you will also be confidential and kept securely and separate from the rest of your data.

9. What will happen to the findings from this study?

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish. The findings will also form the basis of Laurie's PhD thesis for examination by the University of Liverpool.

10. What will happen if I decide I do not want to continue taking part?

If at any time you decide you do not want to carry on taking part in the study it is not a problem. This is not a problem. Your participation is entirely voluntary and your withdrawal will have no consequences for you whatsoever. You will need to contact Laurie Dunn on 0151 794 8043 or Professor Lloyd-Williams on 0151 794 5605 to tell them you have changed your mind.

11. Who do I contact if I have further questions?

If you have any more questions about this study, please contact Laurie Dunn on 0151 794 8043 or at ldunn@liv.ac.uk or Prof. Mari Lloyd-Williams on 0151 794 5605 or email her at mlw@liv.ac.uk.

Appendix 3: Consent Form



CONSENT FORM

Title of Research Project:

Dying from end stage respiratory disease, neurological disease and cancer in the 21st Century: What is the current experience for patients and carers and what makes a difference for carers?

Principal Investigator: Professor Mari Lloyd Williams, Honorary Consultant in Palliative Medicine, Academic Palliative and supportive Care Studies Group, School of Population, Community and Behavioural Science (email: mlw@liv.ac.uk Tel: 01517945605)

Laurie Dunn, PhD student (email: ldunn@liv.ac.uk Tel: 0151 794 8043)

PLEASE INITIAL BOX

1. I have read and understood the participant information sheet Version 1, dated (04/06/10) for this study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving a reason or my statutory rights being affected. ☐
3. I understand that under the Data Protection Act, I can ask at any time to access the information I provide. I can also request the destruction of this information if I wish. ☐
4. I understand that my interview will be audio recorded. I agree to this and to the use of any information I give being used in anonymous form in publications, conference presentations or similar events. ☐
5. I agree to take part in the above study. ☐

<hr/>	<hr/>	<hr/>
Participant Name	Date	Signature

<hr/>	<hr/>	<hr/>
Researcher Name	Date	Signature

Appendix 4: Interview Guide

Interview guide:

- 1) Diagnosis and illness trajectory: What were the problems and how were these addressed?
- 2) What support was offered? How effective was that support? What was good and not so good?
- 3) What would have made a difference for the patient and the carer?
- 4) Financial aspects of care that you would like to talk about? E.g. carer's allowance
- 5) Do you think that x was cared for in a dignified way (in hospital/hospice/by carers at home)?
- 6) Were palliative care needs addressed (i.e. physical symptoms, emotional and spiritual needs and needs of carers)? If so, how, when and where?
- 7) What happened in last few weeks of life? What was good and what could have been better?
- 8) Was there a choice regarding place of death?
- 9) Where did patient die? What was the experience of carer?
- 10) Bereavement support.
- 11) Most positive aspect of care?

Appendix 5: Distress Protocol



Dying from end stage respiratory disease, neurological disease and cancer in the 21st Century: What is the current experience for patients and carers and what makes a difference for carers?

DISTRESS PROTOCOL

In the event of a study participant becoming distressed the following courses of action will be taken:

Distress exhibited by participants prior to the interview will be sensitively addressed by the researcher. The cause of the distress will be established and discussed if the participant wishes. The researcher, in collaboration with the participant, will establish whether to proceed with the interview, re-schedule or discontinue inclusion in the study.

If participants demonstrate any signs of distress during the interview, the process will be suspended by the researcher and the audio recorder will be switched off. Participants will be allowed to ventilate feelings/emotions if desired. The researcher and participant will collaboratively decide upon their ability to continue the interview following a “time out” period.

If the researcher and participant agree, the interview will proceed.

If the level of distress exhibited necessitates complete suspension of the interview, both the researcher and the participant will discuss the appropriateness of re-scheduling. If both agree that the level of distress warrants withdrawal from the study, this will occur, without penalty for the participant.

If the interview is re-scheduled, the researcher will be aware of the potential for distress and act accordingly during the future visit.

If distress occurs following the interview, the researcher will sensitively address this in collaboration with the participant.

The researcher will establish if the participant wishes any data obtained to be used in the final analysis. Wishes of participant will be respected.

The researcher and participant will collaboratively identify ways of seeking support regarding any issues that caused distress during the interview. This may include a referral to their G.P., supportive groups or counselling services. The researcher will have a list of potential sources of help.

Appendix 6: Example of Field Notes

Field Notes: The interview with Pauline took place at her home on [date]. Pauline was very welcoming when I arrived and we chatted whilst she made us a drink. She also showed me photos of her husband before his illness. This progressed into her beginning to tell me about their story. After a few minutes and at a suitable point I asked if we could go through the consent forms and start the tape, in order to avoid asking her to have to repeat herself too much. She was happy to do this.

Pauline heard about the study through a local carers' newsletter. She said that she wanted to take part in the study so that it could hopefully help others in the future and also wanted to say how positive her experience of palliative care was, and how there should be more funding available for hospices.

Pauline was teary at times during the interview, but was not distressed.

Pauline's husband had small cell lung cancer with brain metastasis. Although lung cancer was the primary cancer, his symptoms were connected to the brain metastasis. He suffered from many seizures during his illness, which they later found out could have been triggered to either or both of the cancers. This resulted in many difficulties in terms of his hospital care, as he was put on to a lung ward, as the neurological wards would not take him as they weren't treating him. However, as his symptoms were largely neurological, Pauline felt that the care on the lung ward was not suitable for his condition.

The main points Pauline emphasised in the interview were: the poor communication between departments and hospitals where her husband was being treated; feeling 'unwanted' on the lung ward, as her husband's symptoms were neurological; the excellent care they received in the palliative care unit of the hospital.

After the interview Pauline thanked me for listening to her and said that she had not had the opportunity to speak about her experience and her feelings in such a way since her husband's death. She also said that she had found the interview quite therapeutic and began to talk about accessing one-to-one bereavement support through the local hospital. She said that she was finding things harder rather than easier to deal with as time went on and that she felt 'lost'. I encouraged her to think

about accessing bereavement support, as she had brought it up, and it seemed like she was reaching out for help.

Observations: Pauline was comfortable using my name freely during the interview. I thought that this showed a good rapport and that she was comfortable in talking to me, and perhaps that she felt we were having a conversation rather than 'an interview'. I also felt this way and more so than in other interviews.

Reflection: I thought that this was a really positive interview with good content for the study as well as allowing Pauline to talk about her husband, which she said she found 'therapeutic'. I felt comfortable in this interview to not follow the usual structure of the interview schedule, but followed the pattern of the conversation with both standard and supplementary questions as the conversation developed.

Appendix 7: Example of Narrative Structural Analysis

Orientation	Complicating actions	Evaluations & resolutions	My interpretations
<p>[131-133] And another night, the one carer that came a lot, she always came, she was always punctual, and by 11 o'clock she wasn't there. So I was concerned about her, because she used to travel on the bus</p>	<p>[133-139] and so I rang the agency to see what had happened, and they said she didn't know where she was, so I said 'Well what happens now? Do you send a substitute?', and it was 'Oh no, you'll get none. There's no back up care'.</p> <p>And fortunately, there was a mix up with them. They'd told N [carer] in the afternoon that her shift was changing, and then not told her that it wasn't changing. So she just didn't come. But they got in touch with her, and she came. She was a couple of hours late, but she came.</p>	<p>[139-144] The point that I'm making is that I'd been up since 7 o'clock that morning, and they expected me to stay up all through the night and the next day, because at that time, I didn't have anyone during the day, it was just me. So I would have been up 48 hours.</p> <p>I: That's a long time...</p> <p>P: Yeah, it is. You know, I'm 62 now, I was 61 then, I couldn't have physically done that.</p> <p>Er, the caring staff that came were fine, but the organisation JL I thought were appalling. Absolutely appalling.</p>	<p><u>What is the point of this story?</u> [participant] is trying to convey her worry and anxiety about being able to physically manage to care for her husband in a dignified way at home.</p> <p>This is the first time we see [participant] bring herself into the situation and at this point I am unsure whether she is worried about being able to manage to care for her husband on little sleep, or if she was feeling the toll on herself.</p>

Appendix 8: Code, Category and Theme Development

